Kent Academic Repository

Petri, Gabor (2018) *"Still Out in the Cold" - Self-advocacy and the Disabled People's Movement.* Doctor of Philosophy (PhD) thesis, University of Kent, Tizard Centre.

"Still Out in the Cold" –

Self-advocacy and the Disabled People's Movement

By Gábor Petri

Thesis submitted in accordance with the requirements of the University of Kent at Canterbury for the degree of Doctor of Philosophy

Abstract: The disabled people's movement has been successful in shaping public policies. Today, disabled people lead and control their representative organisations, with the notable exception of autistic people and people with a learning disability who are still often represented by parents and professionals. This thesis used empirical data from two countries, the UK and Hungary to explore the position of self-advocates in the disability movement and identify factors that help or hinder self-advocacy. Several hindering factors were identified, including economic barriers, rules employed by disability organisations and lack of support to self-advocates. Supporting factors include the internet, the community of autistic people and human rights policies. The study found evidence that disability organisations include self-advocates only in tokenistic ways in their processes The thesis also offers a descriptive Pathways Model and a new, practice-based definition to self-advocacy.

Tizard Centre
University of Kent
December 2018

WORD COUNT: 85,405 WORDS

TABLE OF CONTENTS

3

Acknowledgements

Finally, many people I interviewed for this project stayed in touch, in fact, we have become friends and allies. I am glad I know you all and I hope we can continue to fight future battles together for a better world. Findings of this thesis will hopefully help us prepare for some of the debates waiting for us.

List of Tables and Figures

1 CHAPTER ONE - INTRODUCTION

In September 2018, the United Nations Committee on the Rights of Persons with Disabilities (CRPD Committee), the highest-level disability human rights body in the world published its General Comment 7[1] (CRPD, 2018). This document may surprise its readers because instead of focusing on state laws and policies, it looks at civil society. The text consists of a detailed definition – in fact, multiple definitions – of '*representative organisations*' of disabled people. In other words, the United Nations (UN) attempts to clarify which organisations can speak on behalf of disabled people and which cannot. General Comment 7 includes interpretations and *quasi-definitions* of several other terms such as '*self-advocacy organisations*' and '*organisations of family members of disabled people*' and '*cross-disability organisations*.' Even for those familiar with human rights and public policy matters, it may be somewhat surprising that a high-level international UN-body has attempted to (re)define terms that are used widely in everyday language around the world.[2] Why is the UN setting up policies for matters of civil society? One may also ask: why define terms such as '*disabled people's organisations*' when these terms have already been used for decades around the world? What is the UN trying to achieve by this?

The answer is in the presence of the myriad of organisations around the world that claim to be speaking up for and on behalf of disabled people[3]. They call themselves by various names (charities, associations, NGOs, alliances, disability councils etc.), but what connects them is that they claim to be the voice of disabled people.[4] Terms such as 'disabled people's organisations' (DPOs) have been used extensively in recent decades in disability policies, and

---

[1] General Comment 7 is part of the quasi-jurisprudence of the CRPD Committee under the CRPD and it is considered to be the official interpretation of what certain provisions of the CRPD actually mean.

[2] General Comment 7 has official translations in all the official languages of the United Nations including Chinese, French, Spanish, and Russian. It is expected that quasi-definitions provided by the General Comment will induct debates globally, including in countries where English is not an official language.

[3] The UN website on state reports on the implementation of the CRPD testifies of the intensity of participation of (self-claimed or real) DPOs in over 100 countries (United Nations, 2018a; United Nations, 2018b). It can be assumed that civil society organisations, including various NGOs and DPOs of/for disabled people, have been actively involved in policy-making and disability rights advocacy around the world.

[4] For one key example see the communications of the European Disability Forum (EDF) in which over 100 national and cross-national DPOs work together as members, representing disabled citizens of 34 European countries. The EDF – established and controlled by disabled people – proudly calls itself in public documents '*the voice of 80 million people with disabilities in Europe*' (European Disability Forum, 2018).

it is these collective forms of advocacy that are included in public policy-making around the world.

The prominence of DPOs in policy-making is not accidental. DPOs have been widely recognised in the literature and in public policies as the main drivers of social change through their lobby and participation in policy-making (for example Barnes & Mercer, 2010; Hurst, 1999; Oliver & Barnes, 2012; Shakespeare, 1993). From the early days of modern-day disability advocacy, DPOs have been the *de facto* voices of disabled people. Organisations have been leading the disabled people's movement since its establishment (Oliver, 1997). For example, the Union of Physically Impaired Against Segregation (UPIAS, founded in 1974) in Britain was a key actor in the formative years of the British disability movement (Hasler, 1993; Oliver, 1990; Union of Physically Impaired Against Segregation, 1975).

Since the 1970s, a myriad of DPOs have been established by disabled people, their families and other allies around the world that pursue policy changes and advocate for disabled people. Although it is acknowledged that DPOs speak for or on behalf of disabled people, however, it is not always clear what constitutes a DPO or what differentiates DPOs from other organisations working to influence disability policies. For example, organisations *of* and *for* disabled people are usually seen to be distinct (Callus, 2014; Oliver, 1997). But how can government bodies make a similar distinction when they seek for a 'representative voice' of disabled people to consult with? Indeed, how can disabled people themselves tell which organisation can speak on their behalf and which cannot?

It is this dilemma that the CRPD Committee recognised when they published General Comment 7 because the representation of disabled people through DPOs is increasingly ambiguous. For example, many old membership-based DPOs that once led the disability movement (Oliver, 1997) have been replaced by larger structures – present-day DPOs often run services and rely heavily on public funding which could make their independence questionable. The transformation of DPOs into service providers and charities was not without tensions. Many authors have questioned whether these changes benefitted disabled people or not (Shakespeare, 2006), for instance, because the leadership of organisations has become detached from the people DPOs represent (Oliver & Barnes, 2006). Elsewhere in Europe, government funding has influenced the way DPOs advocate, for instance, many organisations may seek collaboration with state authorities and shy away from openly criticising them (Holland, 2008).

These issues are ever more important because civil society organisations of and for disabled people increasingly participate in policy-making around the world (Birtha, 2014b; Lawson & Priestley, 2013; Malinga & Gumbo, 2016; United Nations, 2018a; United Nations, 2018b). If the agenda of parent-led (or professional-led) DPOs remains influential on public policy but leaves behind issues that are salient for self-advocates, then there is a risk of running reforms that maintain the dis-empowerment of people with disabilities.

On the other hand, DPOs and their leadership matters are not the only ambiguity in today's disability policies. In fact, the problem the General Comment 7 attempts to tackle is not merely about DPOs as opposed to other organisations. The real question behind the elaborate explanations given by General Comment 7 is broader in its scope: who can speak up on behalf of disabled people?

This question is more pertinent than ever. What is often seen as one 'disability movement' is, in fact, a very heterogeneous and fractured collective of different disability groups and organisations. Indeed, it may be hard to see what exactly unites different disability groups and organisations when even a common disability identity is difficult to be established among members of the movement (Beckett, 2006). In fact, a broad range of organisations speak up on behalf of disabled people, including organisations controlled by disabled people (such as people with sensory, physical or psychosocial disabilities), organisations found and led by family members of disabled people, human rights groups (usually operating outside DPOs), and occasionally even organisations advocating for children. Is it possible that all these different types of organisations are authentic voices of disabled people?

This project seeks to answer some of these questions. This research has explored one of the most persistent ambiguities in the disability movement: the case of autistic and learning disability self-advocacy (included in para 12(c) of the General Comment 7[5]).

<center>***</center>

Why investigate self-advocates' position in the disability movement? The idea for this project was rooted in the researcher's experiences as a disability rights advocate and his observation about the lack of visibility of (autistic or learning disability) self-advocacy in DPOs. In this regard, self-advocacy is not a problem one can easily see in the disability movement. On the

---

[5] Findings of this study informed a submission to the *Call for submissions: Draft General Comment No. 7 on articles 4 (3) and 33 (3)* published by the UN CRPD Committee in April 2018. The submission was sent by the Tizard Centre, University of Kent. Link to the submission: https://www.ohchr.org/EN/HRBodies/CRPD/Pages/SubmissionsDraftGC7.aspx (last visited 3 December 2018)

contrary, autistic and learning disability self-advocacy is usually invisible at most events organised on disability-related issues. In the period between 2000 and 2016, the researcher participated in countless meetings, conferences, workshops, public consultations, roundtables, hearings, discussions, board meetings of organisations, parliamentary or council debates, media features etc. across Europe that concerned policies relevant for autistic people or people with a learning disability. However, over 16 years only a small minority of events involved autistic people and people with a learning disability in meaningful ways. It is this personal experience of the researcher that prompted and inspired the present study.

It is also this lack of participation and invisibility that stands in stark contrast with the slogan 'nothing about us without us', cited and repeated infinitely across the disability movement today. Several authors have noted the continuous marginalisation of people with learning disabilities in the disability movement and in Disability Studies from the 1990s (for example Aspis, 2002; Aspis, 1997; Dowse, 2001; Mack, 2005). Autistic people have been also marginalised in advocacy for decades (Waltz, 2013).

Of course, advocates working in the disability movement may feel that things have been changing for the better. There is a growing visibility of autistic and learning disability self-advocacy. In recent years, a series of 'first' events have set things into motion and it can be claimed that autistic people and people with a learning disability are more involved in the disabled people's movement and in policy-making than ever. There are several examples of recent events when self-advocates became 'first' office holders or holders of prominent positions in the disability movement.

- In 2010, US president Barack Obama appointed Ari Ne'eman, an autistic man to the National Council on Disability (NCD), an independent federal agency of the United States. Ne'eman was the first openly autistic person to become a member of the NCD (Baker, 2011).
- In 2013, a 30-year-old Spanish woman, Ángela Covadonga Bachiller '*made history*' by becoming '*Spain's first ever town councillor with Down Syndrome*' (Mills, 2013) in the capital of the autonomous community of Castile and León, Valladolid.
- In 2013, László Bercse, a Hungarian man with a learning disability was elected to the National Disability Committee ['*Országos Fogyatékosügyi Tanács - OFT*'], a Government advisory body on disability policies (Amieletunk, 2013). Bercse is also the first ever co-president with a learning disability at the national organisation ÉFOÉSZ that represents people with learning disabilities and their families.

10

- In 2015, Gavin Harding became the mayor of Selby, a northern English town. Harding is diagnosed with a learning disability and the media proclaimed that the council of Selby *'made history by appointing the UK's first mayor with a learning disability'* (Gander, 2015).

- In 2016, following a concentrated campaign by the global NGO Inclusion International, Robert Martin, an Australian man with a learning disability was elected to the UN Committee on the Rights of Persons with Disabilities (Inclusion International, 2016). The election was called '*historic'* in the press because Martin is the first person with a learning disability who serves on a high-level UN body (Newshub, 2016).

- In 2016, Pietro Cirrincione, an autistic IT-expert and member of several self-advocacy organisations in Rome, Italy was elected the first vice-president of the European umbrella organisation Autism Europe. Upon election, Cirrincione stated '*the presence of people with autism in organisations must be strengthened*' (Autism Europe, 2016).

- In 2016, Gábor Csonka, an engineer living in Budapest became the first autistic Board member and vice-president of the Hungarian Autistic Society, the parent-controlled national umbrella organisation representing autistic people and their families (Albert, 2016).

- In 2017, Senada Halilčević, a Croatian self-advocate with a learning disability became vice-president of Inclusion Europe, the European umbrella representing people with learning disabilities and their families. Halilčević, also president of the European Platform of Self-Advocates (EPSA), is the first person with a learning disability to become vice-president in Inclusion Europe.

- In 2018, the council of *Inclusion Asbl,* the Belgian organisation representing people with learning disabilities and their families elected Mathilde Cotman (Wallonia) and Thibault Appelmans (Flanders) to the Board of Directors (Le Guide Social, 2018). Cotman and Appelmans represent self-advocates with a learning disability in the Board of the Inclusion Asbl.

The list could be continued with similar 'first' elections from around the world. However, the question remains: are these elections signs of real progress in the participation and inclusion of self-advocates in the disability movement (and in policy-making)? Are these events the start of a transformation where self-advocates are gaining control over DPOs? Or are these 'first' events purely symbolic that do little justice to the everyday practices both within DPOs and within the disabled people's movement as a whole?

Whether the above events signal meaningful changes, is unknown at this point. Several recent academic and activist accounts reported that systematic and progressive changes in the inclusion of self-advocates in policy-making (and research) are yet to happen (for example Dowse, 2009; Hild, 2017; Ne'eman, 2010; Parsloe & Holton, 2017; Pellicano, 2012). Notably, there are also signs that the 'historic' changes in the above list may be ambiguous themselves. For example, the nomination of autistic advocate Ari Ne'eman by Barack Obama was halted before final approval, for reasons currently unknown. As Baker (2011, p. 1) writes: '*The seven other nominees were relatively quickly confirmed. Ari Ne'eman was not. In the US Senate, an anonymous hold was put on the motion to allow the vote on his confirmation*.' It is possible that the delayed approval by the US Senate was related to the fact that Ne'eman – unlike other persons nominated by Obama – had a 'cognitive disability'.

Furthermore, some of the self-advocates featured in the above list voiced concerns about the dominance of parent-led organisations. Cirrincione, the vice-president of Autism Europe stated upon his election:

> '*In the field of autism there are several groups whose voices should be heard, and the way of enforcing the rights of people with autism varies depending on the point of view and experience of each of them. For example, some parents have a tendency to protect people on the spectrum, whereas self-advocates favour autonomy. We are all going in the same direction but the route is not the same.' (Autism Europe, 2016)*

It remains a question whether a '*different'* route mentioned by Cirrincione has been followed by Autism Europe since 2016. Can the election of a new board member meaningfully change organisational practices or traditions that favour 'protecting people on the spectrum'?

Tensions between organisations led by self-advocates and those controlled by professionals are also known. Autism Speaks, a US-based charity that claims to be advocating for autistic people has been sternly criticised by the Autistic Self Advocacy Network (ASAN, 2016) for portraying autism as a disease in their fund-raising campaign (McGuire, 2012; Parsloe & Holton, 2017). Thus, it remains an open question whether the marginalisation of self-advocates in the disability movement is being tackled or not. It is possible that autistic people and people with a learning disability are not getting more opportunities to influence advocacy organisations speaking for them.

The objective of this study was to investigate some of these ambiguities by looking at the position of self-advocates in the contemporary disability movement. The study builds on empirical data collected in two countries, the United Kingdom and Hungary, and looks at

factors that help or hinder self-advocates' participation within the movement, including in DPOs. Although the inquiry builds on empirical data from two countries, the study is not a comparative one. Instead, similarities are looked at to give more relevance to findings internationally. In other words, the aim is not only to look at the British and Hungarian disability movements, but also to appraise the position of self-advocacy in the contemporary disability movement and in modern-day DPOs in general.

Internet-based disability advocacy is becoming ever more important in today's disability movement (Pearson & Trevisan, 2015; Trevisan, 2016) therefore it is crucial that novel, online forms of advocacy are also investigated. Therefore, the thesis aims to explore the position of self-advocates in both offline and online forms of contemporary disability advocacy – a closer focus will be given to the salience of the internet as a facilitator of today's self-advocacy.

The following chapter (Chapter 2) provides an overview of previous academic literature on self-advocacy. This chapter includes a look at personal accounts of autistic people and people with a learning disability, outside traditionally understood academic works and some other, sometimes overlooked types of self-advocacy such as case law and human rights studies. Chapter 3 sets out the rationale, the main research question, ethical considerations and the methodology of the study.[6] Then Chapter 4 offers two analyses on conceptualisations of self-advocacy, based on advocates' and self-advocates narratives. The chapter also proposes a new approach to looking at and defining self-advocacy. In Chapter 5, a 'mapping' of the contemporary autistic and learning disability movement will be proposed, based on participants' narratives about their routes to (self-)advocacy. The chapter concludes with a Pathways Model that asserts the typical forms of self-advocacy autistic people or people with a learning disability choose. Chapter 6 looks at the issue of funding and its salience in influencing self-advocacy – here, both individuals' income and organisations' running costs are examined. Chapter 7 takes a closer look at advocacy organisations and their practices to involve self-advocates in their work. The chapter also considers some of the factors behind self-advocates' decisions when they choose to work outside formal organisations.

The thesis concludes with Chapter 8, which – after a brief review of main findings of the study – offers answers to the main research question and asserts some of the main facilitators and barriers of self-advocacy in today's disability movement. The chapter also

---

[6] To illuminate the researcher's decisions throughout the project, additional sections on research methodology will be included in several other chapters as well.

proposes a new model of collective work that may be able to tackle some of the barriers identified in the study.

ON TERMINOLOGY

There have been various, often heated debates on the terminology academia or media should use when speaking about disabled people. Some people choose to use terms such as 'people with intellectual disabilities' or 'people with learning disabilities' or 'people with autism' (usually labelled as 'people first' language), whilst others prefer other designations, most commonly and increasingly 'autistic people' (identity first language) or 'people on the autism spectrum' (Kenny et al., 2015).

Some authors and activists (such as People First groups) have a preference for 'people with learning difficulties' noting that perceived 'disabilities' are social constructions – here, it is claimed, the word 'disability' revokes incapacitation whereas 'difficulty' implies various obstacles people so-labelled face. Such political considerations are often distinct from academic traditions. Depending on the context terms such as 'people with Autism Spectrum Conditions (ASC)' or 'people with Autism Spectrum Disorders (ASD)', or 'people with developmental disorders' are still prevalent in medical sciences or in psychology.

Outside English-speaking countries, we see a similar problem, with various terms being used, refused and challenged at the same time by academics, activists and lay audiences. For example, in Hungarian, special education departments often use '*tanulási akadályozottság*' ['learning hinderance'] instead of '*tanulási nehézség*' ['*learning difficulty*'] that is usually understood to be covering people with mild intellectual disabilities but also those with dyslexia, dysgraphia etc. At the same time, the much-used terms '*értelmi fogyatékossággal élő*' ['*person living with a learning disability*'] and '*értelmi sérült*' ['*intellectually impaired*'] are broadly employed not only in media but also by NGOs, parents' organisations and even self-advocacy groups. To illuminate the importance of translation and the interpretation of certain terms by different groups or individuals, the thesis will offer a linguistic analysis of meanings and definitions employed by (self-)advocates in two countries.

Arguments have been formed by nearly all parties involved: academics coming from different disciplines and *disabled people* (or increasingly in European Union and United Nations documents: '*persons with disabilities*') voice often different views. Moreover, linguistic preferences are inconsistent even geographically: some terms are accepted in the UK but are not preferred or understood in other English-speaking countries.

14

The problem of English terms is further complicated by the fact that English has become the *de facto lingua franca* of the international disability rights movement – many documents written in English are not written by native speakers of the language who may not be aware of British or American linguistic traditions or debates surrounding the use of certain terms.

Despite decades of debates, the problem of terminology seems unsolved. While language changes over time, only one thing remains: language users' likes and dislikes regarding certain terms. As recently noted by literature and disability studies professor Michael Bérubé (Bérubé, 2018):

> '*I remember when the word "neuroatypical" was to be preferred to references to "autists", "autistics" or "people with autism" – until some people decided that "neuroatypical" had the unfortunate effect of suggesting that everyone who is not on the autism spectrum is neurotypical (which is palpably not the case). So, if some people prefer* developmental *or* cognitive *(or some other variant) to* intellectual *disability, I invite them to use those terms in their own work, in the understanding that **no terminological choices are beyond criticism**.'* (Bérubé, 2018 p. 28., emphasis added)

The researcher agrees with Bérubé's insightful point. No terminological preferences are acceptable for everyone. However, for the sake of clarity, decisions must be made, therefore this thesis will employ the terms *'people with learning disabilities'* and *'autistic people'*[7], acknowledging that many people so-labelled may have a preference to be referred to by other terms.

---

[7] The two preferred terms are also the terms that most self-advocate participants used in this study. (The use of the term 'autistic people' is also consistent with the findings of a recent study on the preferred terms in Britain (Kenny et al., 2015)). The project builds on empirical data from both English and Hungarian participants, therefore the terminological decisions taken in the English text will need be reconsidered in Hungarian publications, making it acceptable for Hungarian audience. Most likely, terms in Hungarian reports – following linguistic traditions and users' preferences expressed by activists – will be 'autista emberek' [autistic people] and 'értelmi fogyatékos' / 'értelmi sérült' [intellectually disabled] / [intellectually impaired].

2 CHAPTER TWO – LITERATURE REVIEW

This chapter reviews existing literature about advocacy and self-advocacy in learning disabilities and autism. Although much of the literature review will be built on existing English language academic sources, where relevant, Hungarian studies will also be cited to highlight similarities or differences.

The aim of this chapter is to explore current thinking about self-advocacy: relevant literature will be presented, gaps will be highlighted and questions that need further exploration will be considered.

LEVELS OF SELF-ADVOCACY

Self-advocacy in learning disability and autism is part of the broader disability movement that is composed of all groups of disabled people (Barnes & Mercer, 2010; Beckett, 2006; Goodley, 2011; Oliver & Barnes, 2006; Papp, Pál, & Keszi, 2014; Shakespeare, 2013; Trevisan, 2016). Although the term 'disability movement' is widely used in academia (Oliver, 1997; Goodley, 2011; Hasler, 1993; Pelka, 2012; Shakespeare, 2013) and in civil society (for example European Disability Forum, 2017), it is apparent that there is no common agreement on what the disability movement actually means (Beckett, 2006), where its boundaries lie and what it means to members of the movement. Also, while acknowledging that self-advocacy is part of the broader disability movement (Aspis, 1997; Goodley, 2011; Malinga & Gumbo, 2016; McColl & Boyce, 2003), there are differences and tensions between groups of disabled people that must be explored in order to understand where self-advocacy stands today in the disabled people's movement.

Similar to the disability movement as a whole, the self-advocacy movement has been growing rapidly in the last decades (Buchanan & Walmsley, 2006; Chapman, 2005; Dowse, 2001; Dybwad & Bersani, 1996; Goodley & Ramcharan, 2010; Gray & Jackson, 2002; Hurst, 1999; McGuire, 2012; Nagase, 2016; Shore, 2004; Silberman, 2015; Simplican, 2015; Tilley, 2006a; Waltz, 2013; Ward, 1998; Wehmeyer, Bersani, & Gagne, 2000; Whittell, Ramcharan, & Cardiff, 1998). The growing movement has also brought about an increasing body of academic and other literature, for example, personal accounts of autistic people or people with a learning disability (to be reviewed later).

Researchers have employed different definitions of self-advocacy. In his pivotal book, Goodley observed that self-advocacy '*means so much to so many and has grown in*

16

complexity over the years' (2000, p. 8). Elsewhere, he also asserted that self-advocacy can be '*defined as the public recognition of the resilience of people with learning difficulties*' (Goodley, 2005, p. 333). Walmsley gives a somewhat broader definition, emphasising self-representation against representation done by others: '*self-advocacy is about people with learning difficulties advocating for their own needs rather having their needs represented by others*' (Walmsley, 2002), and this definition is seconded by self-advocacy organisations such as People First (Whittell et al., 1998), the European Platform of Self-advocates (EPSA, 2017) and the US-based Autistic Self-Advocacy Network (ASAN, 2016). Others caution that formal and informal ways of self-advocating are not always clear and some forms of individual advocacy may have been present throughout human history (Gray & Jackson, 2002), such as standing up for oneself or for someone else in informal ways. In a recent study, using a grounded theory approach, data showed that people with learning disabilities themselves attach many different meanings to the word 'advocacy' (Llewellyn & Northway, 2008). Historical overviews and personal accounts of self-advocates are in agreement that self-advocacy attempts to bring or facilitate change in the lives of people with intellectual disabilities or autism (Aspis, 2002; Buchanan & Walmsley, 2006; Gray & Jackson, 2002; Shore, 2004; Tilley, 2006a; Waltz, 2013). Recent accounts emphasise that advocacy and self-advocacy include speaking up, lobbying for policy changes and human rights-based monitoring of rights and services. Notably, disability human rights advocacy sees DPOs central to advocacy (Malinga & Gumbo, 2016).

Self-advocacy has had different constructions throughout history (Buchanan & Walmsley, 2006), therefore any definition of self-advocacy is contingent on the historical and societal contexts it works within. Chapman argues that self-advocacy is exercised through '**groups of people** *with learning disabilities speaking up for themselves*' (2005, emphasis added) and others emphasise that collective self-advocacy may achieve more than individual advocacy (Flynn & Ward, 1991). However, self-advocacy is more often discussed as being *both* a collective and a personal form of activity (Dowse, 2001; García-Iriarte, O'Brien, McConkey, Wolfe, & O'Doherty, 2014; Goodley, 2000; Llewellyn & Northway, 2008; Mitchell et al., 2006; Mittler, 1996; Sutcliffe & Simons, 1993; Tilley, 2006a).

Terminology may also be problematic. 'Advocacy' and 'self-advocacy' are sometimes used as synonyms, for example in the preface of an early publication dedicated to self-advocacy and empowerment (Ward, 1998, p. 27) the word 'advocacy' is used: '*It [advocacy] is about giving people voices and choices in their own lives*.' In the context of North American autism advocacy, the term 'advocacy' is often employed even when advocacy is done by autistic

17

people themselves (McGuire, 2012) and a distinction is made by different adjectives: *autistic* advocacy (by autistic self-advocates) vs *autism* advocacy (advocacy done by others). Researchers note that means and language are also distinguishable between the two – autistic vs. autism – advocacy movements (Orsini & Smith, 2010). The difference between these two 'types' of advocacy is similar to the historical differentiation between organisations *of* and *for* disabled people (Callus, 2014; Oliver, 1990; Oliver & Barnes, 2012; Shakespeare, 2013), and a distinction between organisations *of* and *for* people with learning disabilities or autistic people (Bertilsdotter, Brownlow, & O'Dell, 2015; Chamak, 2008; Gray & Jackson, 2002; Waltz, 2013; Waltz, Bosch, Ebben, Hal, & Schippers, 2015; Wehmeyer et al., 2000).

Self-advocacy may also be differentiated from other types of advocacy such as citizen advocacy (Flynn & Ward, 1991), parent/carer advocacy (Hess, Molina, & Kozleski, 2006; Walmsley, Tilley, Dumbleton, & Bardsley, 2017), peer advocacy (Shore, 2004) or professional advocacy (Forbat & Atkinson, 2005; Goodley & Ramcharan, 2010; Walmsley, 2002).

It remains unclear what members of the learning disability and autism advocacy movements think about 'types' of advocacy. It is also possible that members of the autism and learning disability movements do not agree on terminological issues. In fact, there have already been extensive debates about person first vs identity first language (Davidson, 2008; Kenny et al., 2015). Recently, it was found that a majority of British autistic people prefer to be called 'autistic' while professionals may still prefer to use 'person with autism' (Kenny et al., 2015). In fact, language represents dominant cultural narratives (Broderick & Ne'eman, 2008). Language, including terminology and metaphors used by professionals, charities or parents can be seen disabling or offensive for autistic people. Self-advocates often use counter-narratives such as metaphoric language to fight medicalised understandings of autism (Broderick & Ne'eman, 2008). It is possible that ambiguities about terminology also exist in the context of advocacy/self-advocacy.

In the following section, three contexts – or levels – of self-advocacy will be introduced: the personal or micro-level, the collective or meso-level, and the social movement or macro-level of self-advocacy, which also mark three respective, although often overlapping areas of academic inquiries into the nature and practice of contemporary disability advocacy.

2.1 MICRO-LEVEL: SELF-ADVOCACY IS PERSONAL

Self-advocacy is often seen as a form of *personal* resistance against oppressive practices (Caldwell, 2011; Finlay & Lyons, 1998; Goodley, 2000; Mitchell et al., 2006; Roets & Goodley,

2008; Traustadóttir, 2006), therefore many studies about self-advocacy put the main emphasis on personal stories and perspectives. There are many reasons why personal accounts should be taken seriously. Life histories *'enable people to represent themselves as fully human beings and show the beginnings of the resistance movement'* (Atkinson, 2010, p. 9). Furthermore, in the absence of organised self-advocacy groups, people with intellectual disabilities can still speak up and advocate for themselves, for example in hospitals or close wards (Owen, 2006; Tilley, 2006a). Importantly, to 'speak up' refers to not only oral but also other types of communication such as augmentative and alternative communication.[8]

A comprehensive review of research and other literature by Ramcharan & Grant (2001) asserts that three categories can be established when the life experiences of people with learning disabilities are looked at:

- 'testaments of life' (mostly life stories and ethnography);
- 'user movement media' (books, pamphlets, videos, and electronic communication);
- 'research-based studies' that aim to shed light on the lived experiences of people with learning disabilities by using various methodology, including participatory research.

In the following section, Ramcharan & Grant's three categories will be reframed and amended, based on the developments of recent years: three different types of *personal* self-advocacy will be appraised.

2.1.1 Life history and personal identity

Life histories shed light on both individual and collective experiences of self-advocates. Personal histories are usually told by self-advocates themselves, with or without the support of advisors or researchers (Atkinson, 1998; Atkinson, McCarthy, Walmsley, Cooper, & Ferris, 1999; Atkinson, Cooper, & Ferris, 2006; Dybwad & Bersani, 1996; Goodley, 2000; Hreinsdóttir, Stefánsdóttir, Lewthwaite, Ledger, & Shufflebotham, 2006; Shore, 2004; Spedding, Harkness, Townson, Docherty, & Chapman, 2002). Such personal histories and narrative studies reveal that self-advocacy exists outside of formally established self-advocacy groups (Goodley, 2005), for example when people are telling their stories of *'resilience'*, a term widely used in literature on self-advocacy, coined by Goodley's seminal work (2000).

---

[8] This thesis will employ the term 'speaking up' in its broader, inclusive meaning that includes both oral and also non-verbal forms of advocacy.

The reason for the focus on life histories is epistemological (Goodley, 2001). As revealed in a comprehensive literature review, when developing and presenting knowledge about people with learning disabilities, the perceptions and beliefs of parents and professionals were dominant until the 1980s, lacking attention to personal accounts of those labelled disabled (Whittemore, Langness, & Koegel, 1986). Life story telling, of course, has its limitations for people with learning disabilities, for example, because stories are incomplete, there is a risk of bias, and inarticulateness, or unresponsiveness (Booth & Booth, 1996). However, despite limitations, life histories and storytelling powerfully illuminate the everyday struggles of disabled people, and they represent a popular genre in academic literature, for multiple reasons.

For example, life stories are fundamental in establishing ourselves as persons and have our voices heard:

> *'Life stories and the opportunity to tell them, are particularly important for people with learning disabilities because they often have been silent, or silenced, while other people – families, practitioners, historians – have spoken on their behalf. Life stories begin to redress that balance as they become a means by which people with learning disabilities have a voice that is theirs'* (Atkinson, 2010, p. 8)

Furthermore, narrative inquiries allow people with learning disabilities to speak up and demonstrate that it is possible to survive an oppressive system (Dybwad & Bersani, 1996; Goodley et al., 2000; Goodley, 2000; Grove, 2015; Hamilton & Atkinson, 2009; Roets, Adams, & Hove, 2006; Traustadóttir, 2006). Personal histories are able to expose patterns of multiple discrimination, such as disabled women's fights against unfair procedures, neglect and abuse (Atkinson, 1998; Atkinson et al., 1999; Douglas & Harpur, 2016; Stefánsdóttir & Traustadóttir, 2006). Telling life stories to each other may even form a basis for a new type of cooperation between disabled people and society that could be the start of a new way of policy making (Meininger, 2010). Speaking up and speaking to peers, as it is done in life story telling, are both indispensable elements of advocacy.

Disability research itself can be empowering when it enables people with learning disabilities to do research on their own personal histories and share those with others, for example in self-advocacy groups (Atkinson, 2004). Storytelling as an everyday activity can lead to higher self-esteem, better social inclusion and it enables people with learning disabilities to advocate for themselves (Grove, 2015). Such empowerment can eventually have implications on both the storyteller, the listener and the wider society (Atkinson, 1998;

Atkinson, 2004; Meininger, 2010; Shore, 2004). Personal stories also account for one's personal identity, which is of paramount importance for people with learning disabilities and for autistic people, because common, for instance, medical or legal understandings of disability and stigma shape how people see themselves (Goodley et al., 2000; Atkinson, 2010; Tilley, 2006a).

Academic inquiries into self-advocates' individual identities often look at issues such as identification with the label 'learning disability' inside and outside self-advocacy groups (Finlay & Lyons, 1998), views on and relationship to other disability organisations (Caldwell, 2011), the impact of stigma on disabled people's identity (Spassiani & Friedman, 2014), or, in autism, the possible ways to openly disclose oneself as autistic (Davidson & Henderson, 2010). Sociological studies show that autistic people's identities may be influenced by online games such as 'Second Life' which potentially enable them to join activist movements (Bloustien & Wood, 2016), and similar shifts in identity – for example from a biomedical identity toward a more positive, cultural one – were found in studies about online forums where autistic people share their personal stories and ideas with each other (Parsloe, 2015).

Personal narratives are always related to the political realm. Identities of self-advocates are continuously shaped by political discourse, societal barriers, and opportunities, but identities themselves also impact on how groups, organisations or social movements work. One way autistic people or people with a learning disability connect with the public is when they share their life stories in published (auto)biographies.

2.1.2 Autobiographies and internet activism

Autobiographies and online activism form a second type of individual self-advocacy. Biographies and autobiographies are distinct from personal stories in that they exist outside of research and are also popular as a literary genre. Although autobiographies can be written or commissioned by people with intellectual disabilities (Atkinson, 2010), the genre remains more popular in autism. Indeed, autobiographies in book format or online personal blogs are popular mediums for autistic people. In fact, it is claimed that (online or offline) autism narratives – sometimes called 'autie-biographies' – are a '*boom industry*' (Hacking, 2009). According to Hacking, autistic narratives are an important element in the development of the autistic spectrum itself by not only telling what autism *has been* to the broader audience but by allowing autistic people to contribute to the formation of a new autism narrative (Hacking, 2009).

Similar to life stories of people with learning disabilities, testimonies of autistic individuals tell about their personal experiences, including often very private or intimate details of their lives. Such personal accounts include books (for example, Gerland, 2003; Grandin, 2009; Haselfux, 1995; Lawson, 2001; Oravecz & Orosz, 2017; Seth, 2005; Williams, 1992) that have reached not only the wider society but also researchers and professionals who highly value the personal insights into the autistic experience – autistic biographies are used as quasi scientific sources in psychology and psychiatry (Feinstein, 2010; Frith, 2008; Roth, Barson, Hoekstra, Pasco, & Whatson, 2010; Volkmar & Wiesner, 2009). Some of these autistic biographies have also appeared on television or film (Bérubé, 2018), entering popular culture and reaching an even broader audience, whilst still retaining an authentic representation of the original biographies (Lashley, 2016). Personal reflections and collected life stories of autistic people, compiled and edited by an autistic author, can even challenge mainstream concepts and policies such as special or inclusive education (Sainsbury, 2009).

Not all life stories are edited into one single volume of book. Often, they are published bit by bit in the form of online blogs. During the 2000s, and increasingly in the 2010s, a range of online outlets were made available for and created by disabled people that allowed them to formulate and communicate their own ideas, experiences, stories, and complaints – speaking up and 'telling our stories' have become widely common through personalised websites such as blogs, video blogs ('vlogs'), YouTube channels, and social media (Facebook, Tumblr, email groups and chat rooms etc.). The rise of online disability activism is happening parallel with the popular use of internet by other social groups for social resistance, where new communication technologies are a '*basis for a new politics of alliance and solidarity to overcome the limitations of postmodern identity politics*' (Kahn & Kellner, 2004; Pearson & Trevisan, 2015; Trevisan, 2016). In fact, the internet can provide social movements with novel opportunities to organise themselves, to reach out to the public or to influence mainstream politics (Earl & Kimport, 2011). The example of internet activism clearly demonstrates that self-advocacy does not exist in a vacuum but is contingent on societal and technological changes in the broader society and social movements.

The 'internet explosion' was crucial in establishing platforms for autistic people. With the help of the World Wide Web, autistic people formed new networks and shaped the discourse on autism – in fact, the use of the internet empowered autistic people internationally (Bagatell, 2010; Dekker, 1999; Silberman, 2015). Internet-based communication and online activism are particularly suitable for autistic people because the internet is able to provide with more pace flexibility, more control over their messages and lesser social pressure, or

even anonymity (Benford & Standen, 2009; Masschelein & Van Goidsenhoven, 2016). For autistic writer and leading self-advocate Ari Ne'eman, the internet made geographic distance and nonverbal communication 'less relevant' in autism advocacy (Ne'eman, 2010). The internet is '*essential*' for the interaction between autistic people and it facilitates self-advocacy thereby creating space for '*autistic culture*' (Dekker, 1999). The internet may potentially bind individual autistic voices together '*contributing to the creation of a collective voice and 'movement', one that contests predominant constructions of AS [autistic] difference as disorder or disability*' (Davidson, 2008, p. 802). The World Wide Web has also played an important role in the history of early autistic advocacy where people on the spectrum were able to form online communities through email lists and chatrooms (Dekker, 1999; Silberman, 2015; Sinclair, 2005; Waltz, 2013) and we can expect it to be a continuously important platform for new ways of autistic advocacy.

The above assertions are confirmed by the host of personal blogs, social media accounts, Facebook groups and websites that allow people on the autism spectrum to connect with each other, inform their communities or celebrate their identities. In fact, internet activism can be a leading force. For example, in Hungary, in the absence of a strong self-advocacy movement, personal blogs, YouTube channels and Facebook pages by autistic individuals, followed by thousands of people are the main media for autistic voices (for example Asperger+, 2016; Oravecz & Fekete, 2016; Semota, 2015). These blogs and vlogs often voice demands for social change, which renders them 'de facto' advocacy in Hungary. Additionally, these blogs have been developing a language specific to autistic communities, for example by employing words such as '*neurodiverzitás*' ['neurodiversity'] or '*neurotipikus*' ['neurotypical'], that are both largely unknown to Hungarian audiences. Similar personal blogs or social media profiles are also found in Britain, focusing on a variety of personal and public issues (Lowery, 2016; Rhiannon Salmons, 2016). Online life stories sometimes also feature stories by parents and professionals (Thinking person's guide to autism. 2016).

Importantly, the internet may also present certain risks. In the context of Internet-based self-advocacy, cyberbullying may be a potential point of concern for autistic people (Kowalski & Fedina, 2011) or people with a learning disability.

It is possible that the widespread use of the internet and novel ways of self-expression for self-advocates influence how they position themselves within the disability movement. It is necessary to explore how members of the movement see the role of the internet vis-à-vis self-advocacy.

2.1.3 Case law

Besides life stories by people with learning disabilities, and books or blogs by autistic people, there is a third, albeit unorthodox type of individual advocacy that is often overlooked in existing literature. Case law, testimonies before courts and individual interventions under judicial procedures account for a rarely mentioned yet potentially powerful type of self-advocacy. Strategic litigation has the potential to challenge existing laws and policies, although, compared to other advocacy tools, it is less frequently used by disability organisations (Vanhala, 2010). Court cases involving people with intellectual disabilities or autism can be found both in national and international contexts, and their importance is especially relevant in contemporary disability advocacy (Flynn, 2013; Quinn, Degener, & Bruce, 2002). Case law, court decisions, and personal testimonies before courts are, similarly to life histories, capable of revealing individual life stories of oppression and they also demonstrate that disabled people are able to fight against injustice.

One of the most notable of contemporary judicial cases is probably that of Michelle Dawson. Dawson, a Canadian autistic woman successfully intervened and criticised Applied Behaviour Analysis (ABA) before the Supreme Court of Canada in the case of '*Auton vs British Columbia*' (Waltz, 2013). Although ten public bodies and nine organisations also intervened in the case, the Court acknowledged only Dawson's *amicus curiae* in its judgment and, based on ethical considerations raised by Dawson, decided that British Columbia did not violate relevant legislation when they refused to fund ABA (Orsini & Smith, 2010). Dawson's intervention demonstrates that individual claims and interventions by self-advocates – telling their opinions, 'telling their stories' – can challenge not only technocratic expertise (that of ABA professionals), but also other advocacy organisations' views.

Similar cases found elsewhere, too. In the *London Borough of Hillingdon v. Steven Neary [2011] EWHC 1377 (COP)* case, the British Court of Protection ruled that the 21-year-old autistic man Steven Neary was unlawfully detained in a hospital for a year (Henderson, 2011). Neary's story is not unique. The shocking frequency of similar cases was highlighted in the media when they reported about the case of Neary. For example, the national newspaper The Times ran the title '*Thousands of patients in care homes are drugged and locked up*' (Knowles, 2014). Neary's personal story and his struggle for justice successfully drew attention to the systemic violation of the rights of people with intellectual disabilities or autism in Britain.

Although it would be difficult to argue that disabled people as litigants are always self-advocates in the traditional sense of the word, their cases are relevant to self-advocacy for

24

many reasons. Firstly, strategic litigation (bringing cases to the court in order to influence policy changes) is a recognized tool in disability advocacy (Flynn, 2013; Vanhala, 2010), therefore bringing one's own case to court is advocacy itself, even if the procedure is initiated or supported by others such as family members or barristers. Secondly, both cases mentioned above are legal battles fought within the judicial system by autistic people themselves, with potentially great legal implications for other autistic people: court judgments and case law may influence how the law is developed and applied (Harpur, 2010). Finally, the media attention these cases may receive gives them further importance, bringing struggles for justice into the spotlight for a lay audience – one could argue that this is exactly what advocacy aims to do.

2.2 MESO-LEVEL: SELF-ADVOCACY AS *COLLECTIVE ACTION*

Whereas much of the literature on individual forms of advocacy come from people who have personal experiences in disabilities, books and articles on self-advocacy groups are mostly written by academics. A significant part of scientific literature on self-advocacy has been about self-advocacy groups and advocacy organisations, primarily because groups are more or less formalised which makes it easier for researchers to analyse them (Goodley, 2000).

Self-advocacy groups and advocacy organisations of people with learning disabilities or autistic people are seen as primary actors across academic literature (Azzopardi, 2000; Balázs & Petri, 2010; Bertilsdotter et al., 2015; Birtha, 2014a; Buchanan & Walmsley, 2006; Callus, 2014; Chamak, 2008; R. Chapman, 2005; Crawley, 1988; Dybwad & Bersani, 1996; Goodley & Ramcharan, 2010; Goodley, 2000; Malinga & Gumbo, 2016; McColl & Boyce, 2003; McNally, 2005; Miller & Keys, 1996; Mitchell et al., 2006; Pellicano, 2012; Shore, 2004; Sutcliffe & Simons, 1993; Tideman & Svensson, 2015; Tilley, 2006a; Tilley, 2006b; Tilley, 2013; Tsuda & Smith, 2004; Waltz, 2013; Waltz et al., 2015; Ward, 1998; Wehmeyer et al., 2000). Studies that discuss advocacy organisations focus on a range of issues such as how groups are established or run; representation or power relations within organisations; the role of support workers and advisors; advocacy involving multiple minority groups; internal organisational structures; funding; relationship to the state or statutory bodies; involvement in policy-making and lobby etc.

In the following section, frequent topics in the organisational level of self-advocacy will be presented.

2.2.1 Membership and founding self-advocacy groups

Marking the intersection between the personal and the collective experience of self-advocacy, a regular focus of inquiry in literature is how self-advocacy groups are established, how people join them and what they gain from their membership. Indeed, self-advocacy groups are formed of members, who shape the way they work (Gray & Jackson, 2002).

There is general agreement that joining a self-advocacy group is an important step and can be a life-changer for many, for example, because they can find new friends, develop new hobbies and can also learn how to better speak up for themselves, how to get a paid job, or how to develop new skills (Anderson & Bigby, 2015; Docherty, Harkness, Eardley, Townson, & Chapman, 2006; Docherty et al., 2005; Dybwad & Bersani, 1996; Goodley, 2000; Hoy, Cautrels, & Goodley, 2006; Savage, Wilkinson, & Worth, 2006; Shore, 2004; Spedding et al., 2002; Tilley, 2006a; Whittell et al., 1998). At the same time, Aspis (2017, p. 657) warns that collective self-advocacy carries the risk of '*being modelled on the internalised oppression of people with learning disabilities and lead to low self-esteem and poor self-image*'. In other words, the fact that people work in a collective is not an assurance for its progressive nature.

The two-way relationship between member and organisation is always important in the life of an organisation because it is crucial what people do together. In this regard, studies usually rely on members' views. Personal accounts given by members of groups are often presented in a string or mosaic of stories that mutually complement one another and give a fuller picture of the work of self-advocacy groups. Here lies a real epistemological value of narrative studies in the context of collective self-advocacy, where the reality of everyday action is presented through the eyes of members and potential beneficiaries of the organisation.

Not surprisingly, when asked about the work of their organisations, self-advocates usually share their personal problems and concerns, and how they can overcome difficulties or find solutions for problems together with their peers. Unfair treatment in social services, and neglect or abuse in services or at home are regular concerns group members talk about (Bigby, 2015; Docherty et al., 2006; Docherty et al., 2005; Dybwad & Bersani, 1996; Goodley, 2000; Hoy et al., 2006; Mitchell et al., 2006; Tilley, 2006a). Therefore, much of the work groups do is advocating for members and finding solutions for their problems.

As stated previously, it is often unclear or debated what counts as 'advocacy', and self-advocates' own views on group activities reveal that self-advocacy in its collective form is almost never only about campaigning or going out to speak to the community. Lack of social

network and isolation are recurring topics in narratives of self-advocates which means that leisure activities, 'having fun together' are seen as core activity in most studies (Chapman, 2005; Goodley, 2000; Hoy et al., 2006; O'Brien, Browning, & O'Brien, 1998; Roets & Goodley, 2008; Savage et al., 2006; Tilley, 2006a). This seems to be, because members need to rely on supportive networks of friends and colleagues to develop positive self-identities (Anderson & Bigby, 2015; McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006). As to whether 'fun' is an integral part of self-advocacy or not, there is no consensus in literature. Usually, while social benefits of groups – finding friends, finding a partner, going out – are emphasised, these are often shown as a collateral outcome of collective self-advocacy.

2.2.2 Typologies of self-advocacy groups

Typologies of self-advocacy organisations have been developed by several authors (Crawley, 1988; Goodley, 2000; Mcnally, 2003). Typologies get varied forms: sometimes only self-advocacy groups are grouped into categories, in other studies all advocacy organisations working for people with learning disabilities or autistic people are included (Goodley & Ramcharan, 2010; Walmsley, 2002). Several studies base their own categorisation of self-advocacy organisations on Goodley's typology (2000) where 4 different models of self-advocacy groups were presented. The focus of this typology was on *independence* – for example how groups work together with or independently from other organisations, service providers or statutory bodies:

- First, autonomous or 'ideal' groups like People First organisations are independent in terms of their funding or their time, and advisors or helpers are also independent from services.

- A second model, 'divisional groups' such as MENCAP chapters arose from parent-led organisations or professionals' initiatives, therefore they have access to more resources than autonomous groups. Organising meetings, finding venues or funding activities may be less problematic for these groups, although conflicts with their founding organisations are often present.

- A third type is called the 'coalition' model which finds its origins in organisations founded by other disability groups or more general 'independent living' or umbrella organisations.

- Finally, the fourth model is the 'service-system' model where the group – such as 'residents' group' or 'patients' forum in a hospital' – is composed of users of one service and most of the work the group does is concerned with the service they receive. (Goodley, 2000)

Drawing on a number of previous studies, McNally (2003) established 3 types of organisational models, somehow similarly to Goodley: the autonomous or '*ideal*' model, the divisional or coalition model, and the service system model. He also noted that such typologies often focus on issues like meeting venue or funding sources, and more useful typologies could be developed by looking at the *achievements* of groups. The limitation of both studies was that they were based on the British context of self-advocacy (and advocacy services) which may be different from the context self-advocates' work in other countries.

Typologies that include both self-advocacy organisations and other advocacy groups or organisations such as those led by professionals or parents are scarce. Therefore, there are very few inquiries that conceptualise self-advocacy as part of the broader movement of disabled people and try to understand how different (self-)advocacy organisations and individual initiatives interact, influence or compete with each other.

Typologies as heuristic tools, of course, have their limitations too. Despite the number of typologies developed by academics for (self-)advocacy, several studies observed that self-advocacy groups are often too diverse to be put into a single category, for instance, because one organisation can show features of more than one category at the same time (Goodley, 2000; Mcnally, 2003; Tilley, 2013). This diversity proposes the question of whether there is an 'ideal' type of self-advocacy organisation and what its properties would be.

When we look at *autistic* people's self-organisation, the picture is a bit different. Although traditional self-advocacy groups such as People First chapters may have autistic members, there are distinctive features of another type of collectives that defy categorisation in the above-discussed ways: online ways of collective work among autistic people (Blume, 1997; Ne'eman, 2010; Sinclair, 2005; Waltz, 2013).

Indeed, similarly to individual online activism, autistic people feel comfortable and supported by the way internet-based communication works in the group context (Blume, 1997). They often use online platforms to get in touch with each other, form communities, or plan advocacy action (Bagatell, 2010). Similar to traditional self-advocacy groups, autistic people gain a lot from joining such online groups and chat rooms that are inroads to an 'autistic community': they can get more confidence and meet new friends. In this sense, however, Bagatell warns that the autistic community is '*not a place but a figured-world*' (p. 38). Here, the term '*figured world*' (Holland, 2001) is a '*historical and social phenomenon into which individuals enter or are recruited and which are reproduced and developed by and through the practices of their participants*' (Bagatell, 2010, p 39). Bagatell's emphasis on the

construction of identities (Bagatell, 2007) as members of the autistic community resonates with earlier descriptions of disability identities that are both personal, political and cultural, the three elements being interlinked (Shakespeare, 1996).

In these forms of online autistic communities, it would be difficult to separate the group level from the larger, societal, social movement level of advocacy, because of the very way online groups work: they have no geographical boundaries or timed meetings, require minimal physical infrastructure and insignificant level of involvement by support workers (Sinclair, 2005). At the same time, joining such groups still requires certain skills (literacy, some computer skills), the opportunity to use internet and electronic devices on a regular basis (not necessarily present in poorer regions or in residential institutions), and even language skills: groups in English speaking countries may attract worldwide membership but working knowledge of English is necessary. These limitations may make it impossible for many people to join such groups, for instance those having more profound conditions, non-verbal or illiterate people, or poorer people who simply cannot afford electronic devices. Planning collective action may also be more difficult without personal meetings which imposes a serious problem for successful advocacy actions (Pearson & Trevisan, 2015). It is also questionable how much impact internet blogs make, or how online communities themselves can initiate actions with policy or even political implications (Trevisan, 2016).

To date, studies on the impact of online autistic activism remain scarce. As opposed to traditional and formal self-advocacy groups, in the case of online groups, the emphasis is not necessarily on common action but often on the discourses these communities develop, which puts them outside of previous group typologies. Also, many times online groups may overlap with offline ones: certain members meet each other personally while others abstain. Previous typologies based on meeting venues, the role of support workers, or independent funding makes little sense for online collectives.

Such novel, contemporary ways of online self-advocacy are largely unscrutinised in the literature. It is also unclear from previous – and recent – studies how self-advocates see the benefits of collective versus individual self-advocacy. To analyse how individual and collective forms of self-advocacy relate to the position of self-advocates within the movement, this study will assess how advocates and self-advocates perceive the advantages and disadvantages of collective and individual advocacy.

2.2.3 Organisational conflicts

Self-advocacy groups are not easy to found and there are multiple problems potential members and their supporters face when starting a new group – however, keeping a group alive and meaningful is also a problem. Internal and external conflicts may arise around several issues. Internal matters of self-advocacy organisations are regularly discussed in studies. For example, power imbalances between members of groups and support workers, parents or professional often feature in case-studies. Organisational case studies often focus on how self-advocacy groups can remain independent from external forces such as statutory bodies, other organisations, social services or families (Chapman, 2005; Goodley, 2000; McNally, 2005; Tilley, 2006a; Tilley, 2006b). The role of advisors can often be problematic, mostly because members value their independence both from services or family members, and it is crucial that advisors or support workers don't become dominant (Llewellyn & Northway, 2008).

2.2.4 Funding self-advocacy groups

Finding permanent funding is a regular problem for self-advocacy groups because venues for meetings may cost significant amount of money and organising activities or travelling also need to be funded. Without appropriate funding, organisations may not be able to work at all (Balázs & Petri, 2010; Chapman, 2005; Goodley, 2000). Funding also has impacts on the independence of self-advocacy organisations (Aspis, 1997; Atkinson, 1999; Buchanan & Walmsley, 2006; Forbat & Atkinson, 2005; Goodley & Ramcharan, 2010; Gray & Jackson, 2002), because '*uncertain funding renders self-advocacy groups vulnerable to being used to serve the agendas of others*' (Bigby, 2015).

From the historical perspective, government funding for self-advocacy has boosted the number of groups in Britain in the 2000s, but there is '*a danger of becoming tokenistic as local government begins to subject self-advocacy to the same conditions as other services (contracts, targets and imposed deadlines)*' (Buchanan & Walmsley, 2006 p. 137).

While funding has long been recognised across literature as an important issue in disability politics in general (Oliver, 1990; Oliver & Barnes, 2012), and particularly in the wake of recent decades' neoliberal austerity (Disabled People Against Cuts, 2016; Goodley, Lawthom, & Runswick-Cole, 2014; Slorach, 2015) it has received little attention in the context of self-advocacy (Chapman, 2005; Goodley, 2000; Tilley, 2006a).

One recent study found that the impact of austerity on people with intellectual disabilities and self-advocacy organisations is grave: funding cuts threaten both the existence of self-

advocacy groups and support services for self-advocates in Britain (Runswick-Cole & Goodley, 2015). In another survey, it was found that few self-advocacy groups in Central England were able to continue their work after recent government cuts (Tilley, 2013). Unfortunately, data remains scarce. General inquiries about the reaction of the disability movement to austerity paid little or no attention to the specific funding problems of self-advocacy groups (Oliver & Barnes, 2012; Slorach, 2014; Trevisan, 2016), which may demonstrate the less valued position of self-advocacy within the wider disability movement. Also, although many European governments introduced severe cuts that impacted disabled people's lives after the financial crisis (Hauben, Coucheir, Spooren, McAnaney, & Delfosse, 2012), the response by disabled people's organisations was meek. To date, no academic studies have asserted the nature and effectiveness of anti-austerity disability advocacy internationally, with the only exception of Trevisan's seminal work on British and US online advocacy (Trevisan, 2016). It is possible that online autistic communities – similarly to Britain – reacted actively in several countries. However, in the absence of relevant studies, it is unknown whether online self-advocacy has challenged austerity in European countries.

Financial backgrounds of self-advocates – for example, their low income and how this impacts their lives and their work as advocates – are acknowledged in literature (Goodley et al., 2014; Runswick-Cole & Goodley, 2015), but are rarely emphasised when conceptualising self-advocacy, even though insufficient income has been a recurring problem in members' personal narratives (Wehmeyer et al., 2000). It remains largely unscrutinised whether self-advocates' personal or household income is an invisible and systemic obstacle to accessing self-advocacy collectives. The scarcity of research on personal income is particularly surprising because it is known that disabled people living in the community (Braithwaite & Mont, 2009), and particularly those with intellectual disabilities or autism, are '*grossly over-represented among poor people*' (Beresford, 1996, p. 553), both in Britain, in Hungary and internationally (Inclusion Europe & Inclusion International, 2005). Austerity and poverty may influence how self-advocates work. For example, lack of money may hinder potential members from joining or devoting enough time to self-advocacy, especially in areas where household incomes are particularly low. Therefore, when discussing the funding of self-advocacy, both money available for group expenses and personal income available to self-advocates must be appraised.

Competition for funding may also be an issue. In a study in Hungary, NGOs led by parents and professionals' organisations have been competing for the limited amount of available funding by governments, while no self-advocacy organisations were found at the time of the

study. It was suggested that organisations of professionals and academics were more successful in lobbying for government funds than parents' NGOs which hindered the development of parents' advocacy (Balázs & Petri, 2010). Similar results were presented in a study on East European disability advocacy organisations, which were found to be relying heavily on government funding schemes. Organisations in the region often focus more on service-provision than advocacy projects (Holland, 2008), which might be indicative to the possible funding sources for self-advocacy.

There seems to be a strong relevance of funding on self-advocacy and how it operates. Both collective and individual levels of self-advocacy may be influenced by the availability or the lack of funding and income. To understand how the availability or the lack of resources influence the position of self-advocacy within the disability movement, this study will inquire about how members of the movement see the role of money in self-advocacy.

2.2.5 Other group-related topics: diversity and intersectionality

Self-advocacy groups may have members who have various identities or conditions that impact their lives. Research may focus on how people with severe or multiple disabilities access self-advocacy groups – studies suggest that self-advocacy has a similar meaning for them as for others: '*speaking up for ourselves*' or '*self-determination*' (Sanderson, 1998), even if they rely mostly or only on non-verbal communication (Kálmán & Könczei, 2002). Resistance or resilience for people with high support needs may get different, sometimes individual forms: it may present itself in stereotyped behaviour (Nind, 2006) or challenging behaviour in locked wards (Johnson, 2006).

Attending meetings and participating in debates may be demanding for many and these challenges are particularly hindering for people with severe disabilities. Involving people with severe or multiple disabilities into self-advocacy groups is a contested topic not only by academics but also by self-advocates themselves (Goodley, 2000; Tilley, 2006a). For example, one self-advocate claimed the problem with self-advocacy was

> '*that sometimes it caters to the interests of those with milder disabilities, who usually occupy leadership positions, and ignore the needs of those with more severe disabilities.*' (Mack, 2005).

This statement raises the question of internal power imbalances within self-advocacy groups and organisations, for example between people with lower and people with higher support needs. There is also a special relationship between high support needs and representation, also called 'compulsory capacity' in self-advocacy (Simplican, 2015) – a notion that sees a

32

certain minimum capacity to speak up necessary for self-advocacy. It is regularly questioned by parents and professionals, whether high-functioning autistic advocates can speak for their lower functioning peers (Waltz, 2013). For autistic self-advocates like Arnold L., this debate is highly controversial:

> *'It's funny that nobody ever talks about that problem with other disabilities – for instance, there are some very articulate people who use wheelchairs and there are some other wheelchair users who have intellectual and communication disabilities of all sorts, but they clearly have some needs in common'. (*Waltz, 2013 p. 184)

Members of self-advocacy groups are not only labelled 'intellectually disabled' or 'autistic' but may also belong to other minority groups which can be the basis for a particular group identity. In other words, people are not only 'disabled' but also women, gay or black which cannot be overlooked in multicultural societies when identity politics flourish and prejudices prevail independently from one's abilities or disabilities. Disability studies itself is also inclusive of such intersectionality, because as Goodley states '*a body or mind that is disabled is also one that is raced, gendered, trans/nationally sited, aged, sexualised and classed*' (Goodley, 2011 p. 33). Studies focusing on intersectionality have found that self-advocacy groups are sometimes composed of one particular sub-group of society. However, forming these groups is usually not spontaneous but managed by others with the admitted aim to bring people together who share similar problems or characteristics. Such characteristics include groups for women with intellectual disabilities (Clark, Fry, & Rodgers, 1998; ÉFOÉSZ, 2016b), 'ethnic minorities' (Downer & Ferns, 1998), children or young people (Marchant, 1998; Mental Disability Advocacy Center, 2015; Mittler, 1996; Petri, 2017; Slater, 2012; Tideman & Svensson, 2015) or elderly people's self-advocacy (Fitzgerald, 1998) show that collective action can be formed on the basis of multiple identities.

It remains an open question whether self-advocates and other advocates in the learning disability and autism movement find intersectionality important or relevant in their everyday work.

2.3 MACRO-LEVEL: SELF-ADVOCACY IN THE DISABILITY MOVEMENT

In this third level of self-advocacy, the social movement context will be discussed, because self-advocacy is not only individual resistance or a group activity, but it is part of the broader social movement of disabled people's organisations (Malinga & Gumbo, 2016). In the following section, the movement of self-advocates will be located within the disabled people's movement and core theories will be discussed.

2.3.1 The disability movement and people with intellectual disabilities or autism

Despite developments of the disability movement in Britain and internationally, the marginalisation of people with learning disabilities within the movement has been observed by several authors (Aspis, 2002; Campbell & Oliver, 1996; Chappell, 1998; Chappell, Goodley, & Lawthom, 2001; Dowse, 2001; Garcia Iriarte, 2016; Goodley, 2004; Stalker, 2012). Critical voices demanding equal recognition of people with learning disabilities in the broader disability movement have been heard from the 1990s.

For example, Chappell asserted that the voice of people with learning disabilities is largely missing both from the movement and from the academic discipline called Disability Studies (Chappell, 1998) – a statement found to be valid by others, too (Boxall, 2002; Stalker, 2012). It is also claimed that most studies and books in Disability Studies have ignored the problems of people with learning disabilities because there was too much focus on bodily impairments and intellectual disabilities are '*located in the backwater of disability studies*' (Chappell, 1998). Chappell also likened the ignorance people with learning disabilities face with the experience of disabled women or elderly people – seconding those opinions that highlight that multiple identities are not represented enough within the movement (Dowse, 2001; French, 1993).

An autistic self-advocate's opinion exposes systemic fractions and power relations within the disability movement:

> '*Any attempt by a group of disempowered people to challenge the status quo – to dispute the presumption of their incompetence, to redefine themselves as equals of the empowered class, to assert independence and self-determination – has been met by remarkably similar efforts to discredit them. (…) [they try] to deny that the persons mounting the challenge are really members of the group to which they claim membership. This tactic has been used against disability activists with learning disabilities and psychiatric disabilities as well as against autistic people.*'
> (Sinclair, 2005)[9]

There are multiple reasons why joining the disability movement for people with learning disabilities is difficult. For instance, debates and arguments are difficult for them to follow,

---

[9] Sinclair's note on 'psychiatric disabilities' marks an important parallel between autistic self-advocacy and the growing movement of ex-users and survivors of psychiatry. As noted by Beresford (2012), users, ex-users and survivors of psychiatry voice criticism about the status quo of mental health policies (WNUSP, 2018), demanding more meaningful involvement both in research, advocacy and in policy-making.

and the Social Model itself is too abstract for many self-advocates to understand and interpret it. Information about general knowledge available for the rest of society is limited, or inaccessible (Aspis, 1997; Stalker, 2012). Where people can form groups, there is still a general dominance of non-disabled people (Dowse, 2001). Also, many self-advocacy groups work in relation to services which makes it almost impossible for them to criticise broader societal practices or more structural oppression (Aspis, 1997; Buchanan & Walmsley, 2006; Chappell et al., 2001; Dowse, 2001; Dowse, 2009). The relationship between collective and individual advocacy actions may also be controversial: self-advocates are expected to wait for meetings organised and decisions taken which many of them find difficult (Aspis, 2002). The need for novel ways of advocacy is further stressed by Simone Aspis, a self-advocate herself:

> *'Speaking up is not just about having polite conversations around the table. How many self-advocacy courses provide knowledge and information on how to organise people with learning disabilities' direct action, demonstrations, lobbies at full council meetings and how to influence Government legislation?'* (Aspis, 2002)

As stated, the disability movement looks fragmented and heterogeneous from the inside (Dowse, 2001; Goodley, 2011). There may be a 'hierarchy of impairments' in the movement where people with learning disabilities fight to be recognised other than 'stupid' (Stalker, 2012). Self-advocates may be forced to exercise resilience not only in relation to the society of non-disabled people but also to their peers with physical or other impairments, because people with other disabilities '*are using the medical model'* with them (Simone Aspis, quoted in Campbell and Oliver, 1996, p 121). It was also revealed that in the history of the disability movement such internal hierarchy has been present from the beginning. According to a US-based self-advocate:

> *'…I hate to say but there was a pecking order within the disability community, and people with a cognitive disability were on the bottom of that order. And so nobody wanted to associate with us.'* (Pelka, 2012)

There are also distinctive features and needs that may differentiate people with learning disabilities from other disability groups. For example, personal experiences (as opposed to abstract concepts) are more important to them, because life experiences or concrete examples make things easier to understand (Boxall, 2002; Stalker, 2012). Also, while most disabled people identify with their label ('blind' or 'deaf'), similar identification is often problematic for people with learning disabilities (Beart, 2005; Chappell et al., 2001) which

impacts their participation in the movement that expects them to accept a collective identity (Stalker, 2012).

Although it may appear that self-advocates stand alone with their problems in the disability movement, they have long been represented through often influential organisations established by their families (Waltz, 2013). Parents' organisations are seen as the second of the three waves of advocacy, preceded by professionals' organisations and succeeded by self-advocacy (Bylov, 2006; Wehmeyer et al., 2000). In the following section, the relationship between parent-led organisations and self-advocacy will be explored.

2.3.2 Parents' advocacy organisations and self-advocacy

Parent-led organisations and parent-advocacy have always played an important role in learning disabilities (Goodley & Ramcharan, 2010; Goodley, 2000; Gray & Jackson, 2002; Simplican, 2015; Walmsley et al., 2017; Wehmeyer et al., 2000). In an analysis of the history of the self-advocacy movement in Denmark, it was presented that parents' advocacy movement was the second generation of learning disability advocacy movement: preceded by professionals and succeeded by the self-advocacy movement (Bylov, 2006). (Bylov also reminds us that these phases often overlap.)

Until today, it is advocacy organisations founded and controlled by parents that often act as representatives of the 'field' of intellectual disabilities or autism. In Britain, with the presence of People First groups, this substitute representation is somehow balanced and self-advocacy enjoys a certain level of visibility, but internationally the dominance of parents is still unchallenged: it is parents who represent people with learning disabilities in several 'National Disability Councils' across Europe, for example in Greece, Germany, Hungary, Italy, Latvia, the Netherlands, Norway, Poland, Slovenia, and Spain (European Disability Forum, 2016).

For the movement of autistic self-advocates – also referred to as the neurodiversity movement (Baker, 2011; Ortega, 2009; Ortega, Zorzanelli, & Rios, 2016; Runswick-Cole, 2014) or the autism rights movement (Chamak & Bonniau, 2013) – the connection to the broader disability movement is slightly different, firstly because autism itself is a later 'invention' than intellectual disabilities. Changing diagnostic criteria in the early 1970s have been seen fundamental in the emergence of a stronger autistic community (Bagatell, 2010; Silberman, 2015). In the first decades of autism advocacy, it was parents and families that established organisations (Bagatell, 2010; Balázs & Petri, 2010; Chamak & Bonniau, 2013;

Kemény, Kondor, & Tausz, 2014; Sinclair, 2005; Waltz, 2013; Ward & Meyer, 1999). Autistic self-advocates only got visibility from the late 1990s onwards in organisations.

Parents' organisations and their dominance in autism and learning disability advocacy have been debated by self-advocates from the 1980s on. People First organisations across the US and the UK have been important in establishing organisations led by self-advocates instead of their parents (Chapman, 2005; Whittell et al., 1998). The problem with representation by parents in advocacy was explained by self-advocate Jim Sinclair (quoted in Ward & Meyer, 1999, p. 45), who emphasised that advocacy by parents and professionals cannot substitute that of autistic people.

> *'Parents and professionals acting on behalf of us is not the same as us, speaking of ourselves. Parents and professionals are more concerned about taking care of disabled people, than with freedom and rights for disabled people.'*

Because of similar tensions, Canadian autistic researcher Michelle Dawson argued that the national organisation advocating for autistic people should rename itself.

> *'Autism Society Canada should change its name to reflect its real objectives, membership, and governance. The new name should indicate that this organization is by and for parents, e.g. Parents of Autistic Children Canada.'* (Dawson, 2003).

Despite such strong statements, it remains an open question how autistic self-advocates see the problem of parent-dominated organisations, partly because organisations led by parents are changing, and they start to provide more opportunities for self-advocates than before. For example, in Sweden, autistic members of the parent-led national organisation follow a radical narrative and demand progressive changes such as their full membership and recognition, whilst parents' understanding of progressive changes is a more moderate one (Bertilsdotter et al., 2015). In France, parents' associations are going through a similar reform working together with autistic self-advocates (Chamak & Bonniau, 2013; Chamak, 2008). In the Netherlands, cooperation between autistic self-advocates and other disability groups remains wanting, and parents' organisations are still dominant in the public discourse (Waltz et al., 2015). In Hungary, the national umbrella organisation representing autistic people and their families elected its first autistic board member, Gábor Csonka in 2016 (Albert, 2016). In learning disability, the European Platform of Self Advocates – supported by the parent-led Inclusion Europe – has been growing since its establishment in 2000, and today new self-advocacy groups are joining from Eastern Europe (EPSA, 2017). Indeed, it seems the terrain is changing in the learning disability and autism advocacy movement, and self-advocates are

becoming visible in parents' organisations. Whether such changes are meaningful, remains unexplored. It is an open question how self-advocates and parents see the roles of self-advocates within parent-controlled organisations today – or indeed how self-advocates see the roles of parents in disability advocacy as a whole.

2.3.3 The human rights movement and self-advocacy

Human rights documents such as state reports, UN reviews, and civil society reports are rich in data about the rights and struggles of self-advocates. Disability advocacy, since its start in the 1970s, has been concerned with human rights, often referred to as 'disability rights' (Harpur, 2012; Hurst, 2003; Kanter, 2003; Pelka, 2012; Shakespeare, 2013; Stein, 2007). Since the adoption of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in 2007, and other human rights legislation such as anti-discrimination or equal opportunities laws, disabled people's organisations participate increasingly in human rights mechanisms and today much of the advocacy disabled people do uses the language and concept of human rights.

The gradual development of rights-based legislation has long been an aim for disability advocates (Degener, 2000; García-Iriarte, McConkey, & Gilligan, 2015; Hurst, 1999; Quinn et al., 2002; Stein, 2007; Vanhala, 2010), but not until the adoption of the Americans with Disabilities Act (ADA) (Americans with disabilities act, 1990) did the human rights-based language started to become dominant among disability advocates. According to Degener, '*with the paradigm shift from the medical to the social model of disability, disability has been reclassified as a human rights issue*', where the ADA was a '*major milestone'* on the road toward equality (Degener, 2000). Inspired by the ADA (Quinn & Flynn, 2012), similarly important national laws were adopted both in Britain (Disability discrimination act, 1995) and in Hungary (Hungarian Parliament, 1998) and in almost all countries in Europe since the 1990s (Vanhala, 2015). Such laws were not developed independently from each other because both legal experts and disability activists were actively using existing 'good examples' when drafting new ones – for example, the ADA had an influence on the CRPD, but also on European Union legislation, and European disability rights laws also influenced each other (Quinn & Flynn, 2012; Vanhala, 2015).

The CRPD (UN General Assembly, 2007) itself is the most complex and strongest international disability human rights convention to date. Ever since its ratification, the CRPD has been described by using enthusiastic and sometimes metaphoric language in academic (mostly legal) literature: '*out of darkness, into light'* (Kayess & French, 2008); '*new era or false dawn*?' (Lawson, 2006); a '*moral compass for change'* (Quinn, 2009); and '*a conscience*

38

for the global community on disability issues' (García-Iriarte et al., 2015). The CRPD is most commonly mentioned among legal scholars as a '*new paradigm*' or '*paradigm shift*' (Bartlett, 2012; Harpur, 2010; Harpur, 2012; Kayess & French, 2008; Mittler, 2016; Sabatello & Schulze, 2014) which brings about the 'human rights' model to disability.

Indeed, the CRPD – parallel with Hasler's observation about the role of the Social Model in the disability movement (Hasler, 1993) – has become the '*big idea'* of the international disability movement in the last decade. Similar enthusiasm for the CRPD among local DPOs or grassroots activists is yet to be seen – in the absence of focused research, it is also unclear how self-advocates see the role of the CRPD in their own everyday advocacy, or whether they find the 'human rights model' (Degener, 2014) useful at all. Some recent initiatives suggest that although international human rights mechanisms such as UN conferences are a potential area for self-advocacy, several barriers hinder self-advocates' equal participation. For example, Autistic Minority International, a collective controlled by autistic activists stated repeatedly that UN meetings, their organisation, restrictive accreditation or the costs of travel to human rights meetings present significant boundaries for most autistic self-advocates (Autistic Minority International, 2018). It is possible that self-advocates face several disabling barriers within the human rights movement. However, to date, very few studies have explored the inclusion of people with learning disabilities or autistic people in disability human rights procedures (Birtha, 2014a).

Globalisation is an important context here because the CRPD itself is an international (global) treaty, ratified by 172 countries *globally* (United Nations Office of the High Commissioner on Human Rights, 2016), that was developed in order to be applied *locally*. The Convention's implementation is supported by international (global) organisations such as the United Nations High Commissioner on Human Rights or international DPOs such as the European Disability Forum (EDF), the African Disability Forum, the Arab Organization of Persons with Disabilities, or the International Disability Alliance. These international DPOs organise regular meetings and execute projects for advocates from many countries ensuring that through the international networks of disability organisations there is a regular exchange of knowledge and information.

Such cross-national networks are not unique to the disability field. In recent decades, the globalisation of human rights has brought about a '*global human rights movement'* (Ignatieff, 2003; Nash, 2015). It can be argued that the international network of DPOs, working toward the realisation of the provisions of the CRPD (García-Iriarte et al., 2015; Sabatello & Schulze, 2014), is itself a *global disability rights movement*. Indeed, the alliance

39

of DPOs in the international level is a *'transnational advocacy network'*, a term coined by Margaret Keck and Kathryn Sikkink (1999). Such networks are characterised by having certain shared values, regular exchanges of information, and a common discourse. Their members may include few (not necessarily all) of the following actors: international and domestic NGOs, foundations, local social movements, media, churches or trade unions, intellectuals, bodies of international organisations and bodies of governments (Keck & Sikkink, 1999).

Transnational networks emerge where activists believe in networking, or where international conferences and meetings are organised and make it possible to develop contacts and develop networks (Keck & Sikkink, 1999). Such networking opportunities have been available for some European self-advocates. There are initiatives to bring self-advocates together internationally, for example, the Inclusion International (established and led by parents of people with intellectual disabilities and professionals) has started working toward founding a global network of self-advocates (Nagase, 2016). Similar initiatives have been started for European self-advocates (EPSA, 2017; Inclusion Europe, 2016b). Autism Europe, another international advocacy NGO – established and controlled by parents – has also organised an event for self-advocates under the banner 'European meeting for persons with Asperger syndrome' (Autism Europe, 2013).[10]

One possible way for self-advocates to engage with the disability rights movement is the monitoring of the CRPD which, according to Article 33 para (3) of the Convention, must happen with the *'active and meaningful involvement'* of organisations representing all disabled people (UN General Assembly, 2007). Therefore, regular reporting on the implementation of the CRPD is an exercise for DPOs that must involve *all disabled people*, including self-advocates. The collection of regular civil society reports on the implementation of the CRPD, featured on the website of the United Nation testifies about the work disability organisations do around the world, with or without the meaningful involvement of all disability groups (United Nations, 2018a; United Nations, 2018b).

Indeed, developing and submitting monitoring reports is an exercise which can bring together different disability groups. For example, in Hungary, working on the alternative

---

[10] Notably, human rights watchdogs claim to be a specific type of organisation that is independent of governments and other political influence (Bantekas & Oette, 2013), which includes independence from the very social groups human rights try to protect (Ignatieff, 2003). For example, DPOs have little or no influence on how human rights watchdog organisations operate. This is a potentially controversial point in the work of watchdogs that often reveal gross human rights violations against disabled people. The examination of human rights watchdogs and their relationship to self-advocates or representative organisations of disabled people is outside the scope of the present project.

report to the CRPD proved to be an effective way to work together for different disability organisations (Hungarian Disability Caucus, 2010), that traditionally follow separate agendas and are usually not working in close alliance with each other (Papp et al., 2014).

The full participation of self-advocates in this process (or in other human rights advocacy mechanisms) remains both challenging and largely unscrutinised (Birtha, 2014a). It is unclear how much people with learning disabilities or autistic people know about the CRPD or human rights, or if they have heard about them at all. It must be acknowledged that significant steps have been made by organisations of and for people with learning disabilities to bring human rights closer to self-advocates, for example through easy-to-read manuals, websites, videos and training programmes (ÉFOÉSZ, 2016a; EPSA, 2017; Hungarian Civil Liberties Union, 2016; Inclusion Europe, 2016a; Mittler, 2016; Nagase, 2016). Also, for the first time in the history of the United Nations, the Committee on the Rights of Persons with Disabilities, a committee of the UN saw the election of a member with intellectual disabilities, Robert Martin (Inclusion International, 2016). Although Martin's membership in the Committee can be seen as having only minimal effect on the movement as a whole, but Martin's election can also be symbolic and motivating for self-advocates to work on human rights.

Critical views on human rights have also been voiced. Marxism-inspired critiques claim that ideological foundations of contemporary human rights are partial because human rights are unable to challenge existing structures of power (Žižek, 2005). Critical legal scholars criticise human rights vehemently, for example, because human rights may depoliticise fundamentally political debates (Douzinas, 2013b) or because they fit well with neoliberalism (Douzinas, 2013a). These critiques found followers among disability scholars who emphasised that the modern concept of disability itself is the creation of modern capitalism and industrial societies which created dependence (Davis, 2010; Oliver, 1990; Oliver & Barnes, 2012; Slorach, 2015). Therefore, disabled people, including people with a learning disability or autistic people will see little benefit from human rights, because human rights are unable to contest economic disparity and multiple levels of oppression. This is why it was also claimed that British anti-discrimination laws – hailed by legal scholars (Quinn & Flynn, 2012; Vanhala, 2015) – would never be effective alone, without trying to achieve more profound politico-economic changes (Barnes & Oliver, 1995). Indeed, when we look at austerity measures imposed by governments in Britain, we see no proof that existing human rights laws were able to protect people from losing their benefits or services (for example Disabled People Against Cuts, 2016; Runswick-Cole & Goodley, 2015; Slorach, 2014; Trevisan, 2016).

Similarly, in developing countries such as Uganda or South Africa, human rights advocacy has failed to address the problem of poverty, and malnutrition, which makes enthusiastic statements about universality and social change questionable (Barnes & Sheldon, 2010). The global relevance of what is enshrined in current human rights treaties is also debated. For example, critics claim that *'rights are a western invention, largely premised on western values, norms and contextual assumptions'* and DPOs or other NGOs only provide platform for these ideas to flow from the Global North to the periphery (Grech, 2009) – a statement that may be important when investigating self-advocacy in a post-socialist country like Hungary. Furthermore, the relationship between global human rights organisations and local grassroots groups may be problematic, because global human rights agendas may be different from what local advocates see important (Meyers, 2014). A recent study on the implementation of the CRPD showed that power imbalances between actors working in international and local levels may result in the co-optation of local grassroots disability organisations (Meyers, 2016).

To conclude, the relationship between self-advocacy and the human rights movement of disabled people is a complicated one. It remains unclear how self-advocates engage with the monitoring and the implementation of the CRPD and whether they see human rights tools effective or useful at all. It is also questionable if present human rights initiatives, organised and sponsored mostly by DPOs that are *not controlled by self-advocates*, can effectively reach out to or bring together a network of self-advocates that can enjoy full membership in the international disability rights movement.

2.4 CONCLUSION

This chapter reviewed existing literature, including not only academic literature but also works published by civil society bodies, self-advocates and other advocates, and case law. The review paid particular attention to some typical methodological considerations and decisions academics make when studying self-advocacy – these will be regarded as possible routes to follow when designing the present study.

The review also highlighted several gaps in the literature. These gaps inform the methodology of the project. The below list is not composed of operationalised questions to be proposed during the study. Rather, these are reflections on the issues and open questions emerging from literature.

- **Definition and the concept of self-advocacy**. Is there a consensus on the definition and terminology of self-advocacy?

- **Parents organisations and self-advocacy**. What is the role of parents and their organisations in supporting self-advocacy?

- **Severity of impairment**. Are people with profound or multiple disabilities included in self-advocacy initiatives? How are they seen by members of the movement?

- **Collective vs. individual self-advocacy**. How do members of the movement see individual and collective advocacy? For example, what are the advantages and disadvantages attributed to these forms of advocacy?

- **The internet and its role in contemporary self-advocacy**. Is the internet shaping the way self-advocates work? Is the world wide web influencing their position in the movement?

- **The role of financial resources**. What is the salience of money in self-advocacy? Do income and funding influence the position of self-advocates in the disability movement?

- **The role of identities beyond disability**. Is intersectionality recognised in self-advocacy and the movement? Is this important to self-advocates?

- **Hierarchy within the disability movement**. Do members of the movement perceive a hierarchy within the disability movement, for example between different disability groups?

- **The salience of human rights and the social model**. How do members of the disability movement see human rights and the CRPD?

- **International networks.** Do members of the movement cooperate at the international level?

- **Nothing about us without us.** Are self-advocates meaningfully involved in collective forms of advocacy, for example in DPOs? Do they have control over DPOs?

In the following chapter methodological issues will be discussed, and methods of data collection and analyses will be presented.

3 CHAPTER THREE – METHODOLOGY AND METHODS

There is a long tradition of studying disability advocacy in academic research. Since the dawn of the disability movement, researchers and disability activists have shown an interest in understanding how disabled people speak up against injustice and how they shape the way modern societies see disabled people.

As shown in Chapter 2, self-advocacy presents itself on three different levels: micro (personal), meso (organisational) and macro (social movement) levels. Academic literature, civil society reports and accounts by disabled people have usefully presented issues around how self-advocacy and advocacy work on personal and organisational levels, however, self-advocacy's position in the social movement or macro level has remained largely unscrutinised.

The disabled people's movement is, of course, rather complex in its composition. The movement includes various different disability groups, for example, people with physical disabilities, people with sensory impairments such as blind people, deaf people or hard of hearing people, and others. Historical overviews also demonstrated that the disabled people's movement has influenced public policies over recent decades (Barnes & Mercer, 2010; Sabatello & Schulze, 2014). Similarly to the disability movement as a whole, the *learning disability* and *autism advocacy* movement have also influenced both policies and services around the world (Feinstein, 2010; Hegedűs, Kurunczi, Szepessyné Judik, Pajor, & Könczei, 2009; Pelka, 2012; Waltz, 2013; Wehmeyer et al., 2000).

Self-advocacy by autistic people or people with a learning disability has long coexisted alongside other types of advocacy. In recent decades, significant progress has been made in the inclusion of self-advocates within the disabled people's movement (Bylov, 2006; Waltz, 2013; Wehmeyer et al., 2000). Today, self-advocates are recognised members of disabled people's organisations (DPOs) and the disabled people's movement as a whole. However, academic literature suggests that self-advocates still struggle to be fully included in organisations speaking for them (Bertilsdotter et al., 2015; Chamak & Bonniau, 2013; Waltz et al., 2015), and – as presented in the previous chapter – most DPOs in learning disability and autism are still controlled by parents or professionals. Despite extensive criticism by self-advocates about their lack of meaningful involvement in certain advocacy organisations (Aspis, 2002; Aspis, 1997; Dawson, 2003; García-Iriarte et al., 2014; McGuire, 2012; Ne'eman, 2010), academic studies have been scarce about the involvement of self-advocates in the disabled people's movement or in DPOs. It remains largely unknown what the position of

self-advocates is in the contemporary disability movement, and what are the factors that hinder or facilitate self-advocates to be in control of the learning disability and autism advocacy movement.

This research project sets out to fill this gap and to investigate the position of autistic and learning disability self-advocacy within the social movement of disabled people. The study is interested in factors that influence how self-advocates participate in everyday advocacy alongside their non-disabled peers. The study also aims to look at factors that may help or hinder them in gaining control over organisations or advocacy initiatives. The exploration of such factors requires a research approach that is aware of the complexity of the research environment. Today's disability movement, including learning disability and autism advocacy, and self-advocacy are more complex than ever.

3.1   RESEARCH FOCUS

Studies that have looked at the way self-advocates work together with other advocates have often placed organisations in their foci. Studies on advocacy organisations (for example Balázs & Petri, 2010; Bertilsdotter et al, 2015; Tilley, 2006 etc.) have broadened our knowledge on how self-advocacy groups or self-advocates work together with or within organisations controlled by others such as parents, social services or public authorities. The limitation of these inquiries is that they usually look at one or two organisations and analyse data in an actual organisational context relevant to their members. Such studies flag important issues around various issues including the management, membership or funding of self-advocacy groups, but they are limited in making generalised observations on how self-advocacy is positioned in the disability movement. Other studies have looked at how self-advocates struggle to be recognised in a national context, for example, because power disparities persist between parent-led organisations and self-advocates' groups (Azzopardi, 2000; Bylov, 2006; Chamak & Bonniau, 2013; Chamak, 2008; Waltz et al., 2015). Again, such studies also limit themselves to make specific observations about a national (Maltese, Danish, French, Dutch etc.) disability movement or actual organisations working in a given country.

As seen in Chapter 2, studies focusing on self-advocacy on a macro, social movement level remain scarce. At the end of Chapter 2, several gaps in literature were identified which invite an exploratory study – both to confirm the salience of issues highlighted in Chapter 2, but also to investigate whether there are other factors that influence self-advocates' participation in the disability movement.

The research question is: **'What are the factors that help, and barriers that hinder self-advocates within the disability movement?'**

The context of this inquiry is the disabled people's movement which includes individuals, groups, collectives, both formal and informal communities and organisations, working on local, regional, national or international levels. Projects aiming to inquire about the disability movement need to consider its multi-faceted nature – the context of this project is a highly complex one, for several reasons.

➢ The study looks at the social movement of disabled people that is composed of different *forms of advocacy*: groups and individuals that pursue advocacy and self-advocacy. Here, the inquiry faces many different organisational forms people may establish, join and influence. These forms are highly varied and it is assumed that there is no predefined or ideal form of advocacy. All different forms are relevant to people's lives, preferences and demands. Therefore, the study needs to allow for the inclusion of all possible forms of self-advocacy including, for example:
  o individual self-advocacy,
  o formal self-advocacy groups,
  o informal self-help or peer groups,
  o online collectives,
  o established advocacy organisations,
  o organisations of mixed nature (for instance those led jointly by self-advocates and others; or those representing families that include self-advocates),
  o formal DPOs,
  o umbrella organisations representing more than one type of disability,
  o human rights organisations such as watchdogs that work with self-advocates etc.

➢ Furthermore, the study runs in an environment where organisations', groups' and even individuals' advocacy are influenced and regulated by laws, policies, traditions and various other written and unwritten conventions. These constitute various rules that influence advocates' and self-advocates' behaviour and decisions. Rules may have a strong influence on the position of self-advocates in the movement. Therefore, the study needs to be flexible in this regard and allow for the inclusion of all relevant rules that self-advocates find influential. Rules can be internal, established by organisations or members of the disability movement, such as the founding statutes of a DPO that recognises parents as representatives of people 'with limited capacity', a category assumed to include autistic people or people with a learning disability (European Disability Forum,

2016). Rules can also be external to the disability movement, such as laws and policies. For example, in several countries full legal recognition of those perceived having 'limited mental capacity' hinders self-advocates' political participation such as voting at elections (Fundamental Rights Agency, 2013; Simplican, 2015). The study design needs to be aware of the importance of relevant laws, policies or other formal and informal rules that self-advocates may find disabling.

➢ The complexity of the context is also established by individuals who 'populate' the disabled people's movement: members of groups and organisations, employees and leaders of different organisations and communities but also individual or 'solo' self-advocates. Some of them identify as disabled, others (such as parents or most professional advocates) do not. The study needs to recognise this diversity and include different individuals regardless of their identification as disabled people. Related to identification is a historical tradition in learning disability and autism advocacy that sees advocacy as a multi-party practice, done jointly by self-advocates, parents and professionals. Available historical accounts emphasise that all of these three parties have been influencing autism and learning disability advocacy (Bylov, 2006; Waltz, 2013; Wehmeyer et al., 2000). Studies setting out to investigate the learning disability and autism advocacy movement need to be inclusive of non-disabled individuals that work within the movement. This study recognises the fact that barriers faced by self-advocates may also be perceived by other members of the movement, namely parents and professionals.

➢ The complexity of the disabled people's movement is also highlighted on the international level. Studies have increasingly recognised the social movement of disabled people, including the self-advocacy movement to be an international one (European Disability Forum, 2017; Hurst, 2003; Inclusion Europe, 2016b; Nagase, 2016; Sinclair, 2005). Furthermore, studies on disability human rights issues emphasise that the CRPD is to be implemented on a national level, by States Parties of the United Nations (Quinn, 2009; United Nations, 2018c) – bringing national level disability advocacy to a global context and also bringing global treaties to national relevance. National DPOs increasingly cooperate with each other, for example by joining regional organisations such as the European Disability Forum or the African Disability Forum. National disability rights initiatives are increasingly viewed as domestic chapters of the international disability movement which may constitute one or more transnational advocacy networks (Keck & Sikkink, 1999). Therefore, the complexity of the disability movement is not only constituted by factors within but also by issues without the movement itself – that is a

globalised world where international organisations such as the UN or the European Union increasingly influence both the discourse on disability rights and the opportunities DPOs have. The globalisation of disability rights requires researchers to attempt to step beyond a single national context and appraise self-advocacy by contextualising it beyond the nation-state.

Such complexities make it necessary to rethink previously popular research approaches such as narrative inquiries or organisational case studies, which do not appear to be appropriate for the present research objectives.

3.2 RESEARCH APPROACH

Recognising the above complexities, the design of this research project is set up to fulfil the following requirements:

1. **The inclusion of various forms of self-advocacy**. This study will abstain from putting its focus on one single form of advocacy such as organisations. It will assess both individual and collective forms of advocacy and will analyse data relevant to these forms.

2. **Rules through self-advocates' eyes.** Although a myriad of different rules (laws, policies, written and unwritten conventions, founding statutes and internal rules of DPOs etc.) influence how self-advocacy operates in today's disability movement, the study will focus on the importance of such written and unwritten rules insofar as they are seen relevant and influential to self-advocates in how they participate in the disability movement.

3. **Multi-party approach.** This study is designed to include views and opinions of not only self-advocates but also other advocates who work within the learning disability or autism advocacy movement. The project follows the advice taken from a statement by autistic and non-autistic researchers: '*the ethics of autism research should encompass the various perspectives and best interests of both autistic people and their families*' (Milton, Mills, & Pellicano, 2012). The study puts the experiences of self-advocates at its centre, but builds on the diverse views in the community, including parents[11] and other family members. This approach also follows the tradition used by Waltz (2013), who presented the social history of autism and the current state of the neurodiversity movement by not relying only on self-advocates' written or oral accounts but also on the accounts of other individuals such as professionals and parents.

4. **International relevance**. This study recognises the need for inquiries with an international relevance. The study collects and asserts data from more than one country in

---

[11] Although the study uses the term 'parents', it is important to note that in many cases it is other family members such as siblings who participate in autism and learning disability advocacy.

order to make observations on a cross-national level and also to present findings based on empirical data from more than one country – with the assumption that similarities between countries included in the study will make findings relevant to other countries as well.

3.3   RESEARCH TRADITION

This study adheres to the 'disability studies' tradition. Disability studies has a long history in disability research, dating back to the early days of the British and American disability movement (Barnes & Mercer, 2010; Finkelstein, 1998; Hunt, 1998; Thomas, 2002). In fact, disability studies strongly informed the creation of the disability movement (Finkelstein, 1993), and the way disability studies developed was also shaped by disabled activists (Barnes & Mercer, 2010; Goodley, 2011; Oliver, 1990; Shakespeare, 2013). Although disability studies have grown into a robust and highly diverse field with various international, critical and multidisciplinary branches, this project will adhere to a broadly understood 'disability studies' tradition with the following principles.

Recognising the social model. The study is grounded in the social model of disability. The social model has been described and interpreted by several authors. The popular understanding of the model is that it sets up a dichotomy of two categories, 'impairment' and 'disability'. *'Impairment'* is located in the individual and marks their lack of capacity such or limited functioning, '*disability'*, however, is "*the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities*" (Barnes & Mercer, 2010 p. 137). The social model or 'social barriers model' (Finkelstein, 1993) of disability was called the *'big idea'* of the disability movement (Hasler, 1993; Shakespeare, 2010) that "*emerged out of the direct experience of disabled people themselves*" (Barnes, 1998). The social model gained wider recognition in the 1980s (Barnes, 1998), at the time when disability movements across the Western world expanded. The model is also known in Eastern Europe, for example in Hungary where it has contributed to the development of laws and policies (Kálmán & Könczei, 2002). Although a host of discussions and often heated debates criticised the social model in recent decades, based on feminist, postmodern or critical social theories (for example Bickenbach, Chatterji, Badley, & Üstün, 1999; Corker, 1998; French, 1993; Goodley, 2011; Goodley, Hughes, & Davis, 2012; Shakespeare & Watson, 2001; Shildrick, 2012; Thomas, 2002; Vehmas & Watson, 2014), this study takes inspiration from the social model in its once popularised form: the analysis will look at social barriers hindering self-advocates within the movement.

Contribution to social change. Disability studies have long aimed to contribute to social change which is an important aim of this project, too. This study looks at barriers self-advocates face within the disability movement, with the hope that by flagging certain issues social change can be initiated. It is hoped that revealing systemic barriers and initiating discussion among advocates and self-advocates can contribute to positive changes. Therefore, from the beginning of the project, the research plan included plans to inform not only the academic audience about the findings of the study but also members of the disability movement and policy-makers. This is hoped to be achieved by articles written in lay language – including in easy-read language – in magazines, journals, newsletters, or on websites of DPOs and blogs read by professionals, parents and self-advocates.[12]

Multidisciplinary approach. This study aims to build on theories grounded in different disciplines. Therefore, different chapters will propose different questions for inquiry and will apply relevant literature for analysing data. The aim is to engage with data creatively and use a pragmatic approach to reveal multiple factors hindering or helping self-advocates, and also to give a rich background to participants' views by providing contextual understanding rooted in different disciplines or theoretical traditions. Therefore, disciplines or theories applied to self-advocacy throughout this thesis include social movement studies, practice theory, political theory, law, organisational studies, and media theory. This decision was taken because the project tries to avoid siloed interpretations of highly complex phenomena. The analysis will also engage with language critically, for example by looking at semantic variations of terminology used for self-advocacy.

Qualitative and constructivist methodology. Nearly all studies reviewed in Chapter 2 used qualitative research methods to investigate self-advocacy (a minority of the studies used a mixed-methods approach and included quantitative methods such as surveys). This project will employ a qualitative research design because the study is interested in *how* people see self-advocates' position in the disability movement and aims to map out complex systems of underlying structures, practices or attitudes (or other factors) that help or hinder self-advocates in the disability movement. For identifying these factors, participants' views will be analysed and will be taken at face value, following a subjectivist approach popular in disability studies (Goodley, 2011). It is the 'meaning making' of members of the disability movement that will inform the study about factors hindering or helping self-advocates – here, the project adheres to interpretivist and constructivist traditions.

---

[12] The list of publications based on this study is included in the Appendices.

3.4 POTENTIAL CONTRIBUTION

This study aims to contribute to scientific knowledge about the disabled people's movement. As seen in Chapter 2, researching the social movement of disabled people has been a largely overlooked area in disability studies. On the other hand, social movement studies have equally also been uninterested in the ways disabled people organise themselves to pursue social change (Trevisan, 2016). The project looks at and analyses data relevant to social movement researchers as well as academics interested in disability issues, thereby creating knowledge at the intersection of the two fields.

Furthermore, despite several important recent volumes about autistic and neurodiversity advocacy (for example Baker, 2011; McGuire, 2013; Orsini & Smith, 2010; Simplican, 2015), few researchers have looked at how learning disability advocacy operates at the social movement level. The call for new research into learning disability self-advocacy at the macro level is even more urgent, because although recent developments in disability human rights advocacy have created new spaces for engagement for all disability advocates who speak up against exclusion (Birtha, 2014b), focus on self-advocacy in this context remains sporadic (Birtha, 2014a).

The project is built on empirical data collected in two countries, the United Kingdom and Hungary. In doing so, the study aims to reveal common barriers hindering self-advocates in both countries, with the hope that the presence of certain factors in two countries with different historical, societal and cultural background will give findings more emphasis. Simply put: if self-advocates and their allies see things largely similar in both the UK and Hungary, then it can be assumed that findings may be applicable in many other countries as well. Therefore, this study explores not only barriers before self-advocacy in Britain and/or in Hungary, but it aims to reveal common barriers experienced by self-advocates in other countries as well. This international perspective and applicability of the findings is one of the main contributions of the study.

Furthermore, although disability studies has grown into a fertile and very diverse field in the West, it has a somewhat shorter history in post-socialist countries like Hungary and other Central and Eastern European countries. The body of research published in disability studies is considerably smaller in Hungary. To date, there have only been few inquiries into the history of the Hungarian disability movement (Baár, 2015; Balázs & Petri, 2010; Hegedűs et al., 2009; Papp et al., 2014), with no studies looking at self-advocacy. Therefore, the project aims to produce one of the first reports on the Hungarian disability movement, and the first report on contemporary autistic and learning disability self-advocacy in Hungary.

Finally, this project also aims to fill in another historical gap – that of the silence about the lived experiences of people with learning disability in disability studies. Many researchers have noted that learning disability has been often overlooked in papers following a disability studies tradition. For example, several authors asserted that the voice of people with intellectual disabilities is largely missing both from the movement and from the academic discipline called disability studies (Boxall, 2002; Chappell, 1998; Stalker, 2012). Most researchers in disability studies have ignored the problems of people with learning disabilities (Ryan, 2016) because there was too much focus on bodily impairments. By creating knowledge about various aspects of learning disability self-advocacy, this study attempts to redress this gap.

3.5 RESEARCH METHODOLOGY AND METHODS

This project joins a long tradition of investigating learning disability and autism self-advocacy in academic research. As shown in Chapter 2, the design of previous studies strongly depended on the form or level of (self-)advocacy researchers set out to examine (Table 3.1). Studies on self-advocacy usually employ a post-positivist tradition, relying strongly on narrative and ethnographic methods when looking at individual self-advocates or groups – inquiries into collective self-advocacy often feature case studies of organisations and interviews with leading advocates.

Macro-level self-advocacy	Research approaches / methods
Disability movement	Sociological studies, disability studies
Politics of disability	History of the disability movement, interviews
Disability studies (knowledge and disability)	Human rights implementation, document analysis
Human rights and state reports	Legal theory
Meso-level of self-advocacy	
SA groups, comparative studies	Interviews and focus groups
Case studies of groups	Participatory research
Organisational studies, history of organisations (incl. DPOs)	Ethnography
NGO and DPO documents, reports etc.	
Micro-level of self-advocacy	
Individual SAs	Autobioghraphic approaches / life history
SA groups through the experiences of their members	Narrative interviews
Families and SAs	Ethnography
Parents' stories	Story-telling
Case law	

Table 3.1 Overview of levels of self-advocacy with popular research approaches

This research follows a pragmatic approach and aims to explore facilitators and barriers based on the views of three participant groups:

- self-advocates (both autistic people and people with a learning disability);
- parent-advocates;

- professional advocates[13].

Furthermore, the study is built on empirical data from two countries, which results in a complex set of participants, resulting in a highly diverse group of participants (Figure 3.1). Although participants are united by shared membership in advocacy organisations and in the disability movement as a whole, but they are also separated by different viewpoints (self-advocates vs. professionals; parents vs. professionals; self-advocates vs. parents).

Notably, each participant group includes both people involved in autistic advocacy and those involved in learning disability advocacy which results in yet another type of complexity. Although autism and learning disability may be found to be present in individuals with dual diagnoses, advocacy organisations are often different for autistic people and people with a learning disability. These complexities require careful consideration when analysing self-advocates' experiences, for example by ensuring that data analysis pays attention to the different experiences of different participant groups. Therefore, in later chapters of this thesis, attention will be given to differences between the experiences of autistic self-advocates and self-advocates with a learning disability. It is possible that although some barriers self-advocates face are experienced by both autistic people and people with a learning disability, but some barriers may be more specific to only one of the two groups.
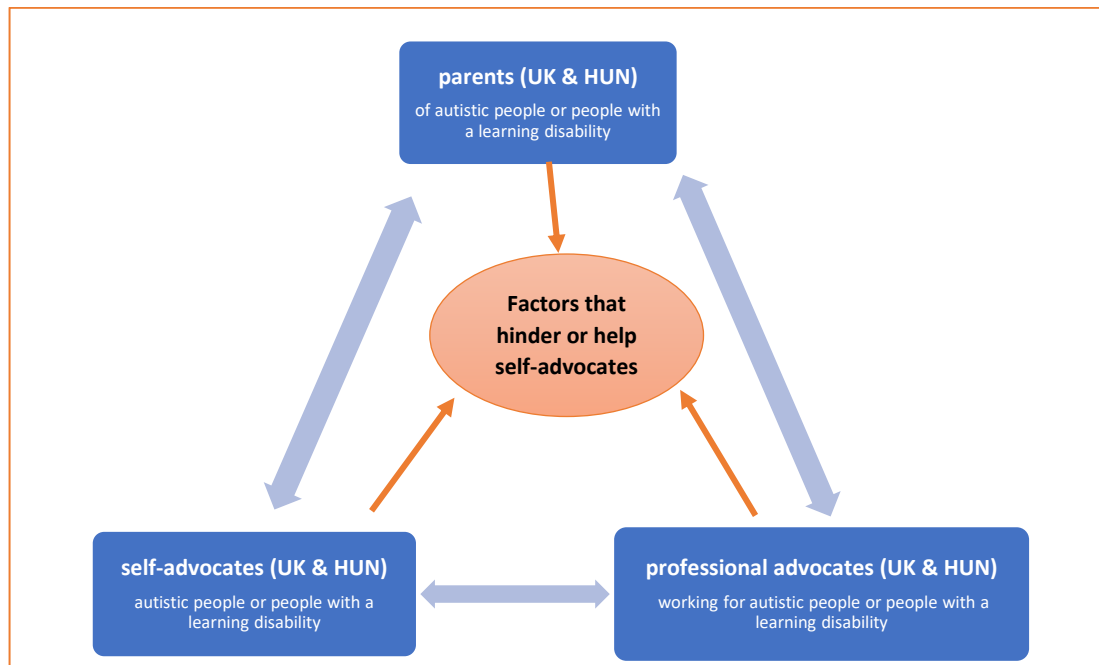
Figure 3.1 Schematic view of participant groups

---

[13] During data collection overlaps were found between two participant groups, professional and parent advocates. Chapter 5 will discuss these overlaps in detail.

The complexity and diversity of the disability movement also required several restrictions, for example in the sampling of participants. For instance, the study includes participants who have worked/have experience in *learning disability* or *autism advocacy*, but not those who advocate for other disability groups such as blind people or wheelchair users. This decision was made in order to keep the focus on the part of the disability movement where autistic self-advocates or self-advocates with a learning disability are the most likely to appear. Therefore, the scope of the study is autistic and learning disability self-advocacy within the learning disability and autism advocacy movement(s).[14]

Participatory research methods are an increasingly popular mode of studying collective self-advocacy and activists and academics – and collectives positioned on the boundaries of activism and research (PARC, 2018) – emphasise its emancipatory nature by giving voice and opportunity to those disabled people who are usually seen as subjects of studies. Participatory research methods are also used when researchers investigate parents' experiences (Walmsley & Mannan, 2009) or in studies where the quality of services is explored in services for autistic people (Balazs et al., 2015). Although participatory methods can shape importantly both the design and outcomes of studies, recent reviews also warn us about the limitations of these projects, for example, because co-researchers with a learning disability do not get involved meaningfully in the interpretation of the data (Strnadová & Walmsley, 2018). On the other hand, participatory methods can ensure that data is not misinterpreted by social researchers, especially if researchers are able to critically reflect on their own limitations and allow co-researchers to participate meaningfully throughout the study (Milton, 2014). Indeed, the lack of participation by disabled people in research aiming to explore their lived experiences runs the risk of 'epistemic violence', a term used by a psychiatric survivor-researcher in the context of the experiences of users of psychiatry (Russo, 2016).

Participatory approaches, which involve co-researchers' in all stages of research would have required the participation of co-investigators from several participant groups in this project. For example Hungarian and British autistic self-advocates; Hungarian and British self-advocates with a learning disability; Hungarian and British parents of autistic people; Hungarian and British parents of people with a learning disability etc. should have

---

[14] As shown in Chapter 2, there are various views on what the 'disability movement' means to its members (for example Beckett, 2006; Trevisan, 2016) and it is outside the scope of this study to solve this debate. Across the study, the terms 'disability movement', 'disabled people's movement', 'disability rights movement' etc. will be used as quasi-synonyms, with occasional signifiers to refer to a certain part of the movement, such as '*learning disability* movement' or '*autism* advocacy movement'.

participated in the design and execution of the project, including data analysis and interpretation. Furthermore, working knowledge of English – the language of the present report – would have been needed for co-researchers who participate in data analysis and interpretation. Such requirements imposed a serious challenge at the design of the project. For example, the involvement of co-researchers would have required some kind of financial reimbursement for their considerable amount of work, which was not available for the project. Therefore, although participatory research design was considered and discussed at several stages of the project, but the extreme diversity of participant groups and the bilingual nature of data put participatory approaches outside the remit of the present doctoral study.

3.5.1 Inductive approach

Methodological choices are always influenced by epistemological considerations, for example how the researcher frames the problem underlying their research question (Durdella, 2017). When studying self-advocacy, epistemological framing – for example, along the line between different models of disability – can influence fundamentally the research design and eventually study findings as well (Goodley, 2001; Goodley, 2000).

For the design of the present study, in the early stages of this project, the researcher considered choosing one of the previously known theoretical frameworks in literature. Different theories can illuminate different facets of the complex experiences disabled people have in contemporary societies, or in this case, within the disability movement. Indeed, there are several concepts that are readily available for researchers, including theories already applied to the study of self-advocacy and the disabled people's movement. For example, dis/ableism (Campbell, 2009; Goodley, 2014) are heralding a diverse field of innovative theoretical concepts, usually under the name 'critical disability studies' (Goodley, 2013; Meekosha & Shuttleworth, 2009; Shildrick, 2012). Dis/ablism can be a useful concept when applied to the study of everyday practices – for example, whether certain structures or mechanisms or discourses are disabling for self-advocates within the disability movement or within DPOs.

Another, increasingly popular approach in current disability research is that of legal studies, where human rights-informed research looks at the 'rights' of disabled people, for example how certain rights are enjoyed or breached in a given context. This research tradition is often seen as working under the 'human rights model' of disability (Degener, 2014; Stein, 2007) and uses legal texts such as the CRPD as core devices for research conceptualisation and research design. Human rights research, in the case of self-advocacy, may look at whether

self-advocates enjoy the rights enshrined in the CRPD with relevance to their 'meaningful involvement' (Article 33 of the CRPD) in the work of DPOs or vis-à-vis governments and state authorities (Birtha, 2014a; Birtha, 2014b).

This research, however, abstains from following any of the above mentioned (or other) traditions when investigating the position of self-advocacy in the disability movement. This is an exploratory study with an *inductive approach* where data collected shape and drive the project as it rolls out, somehow similar to the tradition of 'grounded theory'(Charmaz & Belgrave, 2007). In other words, the study does not aim to verify or apply one particular social theory to self-advocacy. Instead, the approach taken will take inspiration from grounded theory in its openness to data-informed analysis.

3.5.2 Why interviews and focus groups?

Interviews and focus groups (also sometimes called 'group interviews') are popular research methods in qualitative studies to investigate how participants perceive and talk about a given topic. Interviews and focus groups are particularly popular in exploratory studies (Barbour, 2008; Cronin, 2013; Denzin & Lincoln, 1994; Fielding & Thomas, 2013). Both interviews and focus groups are regularly used in constructivist/interpretivist traditions where studies explore a certain phenomenon with the aim to describe people's experiences or feelings and to '*develop theories that describe how factors shape outcomes*' (Durdella, 2017). The latter assertion is particularly relevant here because this study aims to map out factors that *hinder or facilitate self-advocacy and shape self-advocates' lives* within the disability movement.

Interviews and focus groups offer different advantages for researchers investigating social life. Focus groups strongly build on participants' engagement in debates and discussions and see the interaction between participants as the '*hallmark*' of the focus group (Cronin, 2013). Focus groups were a preferred method of collecting data in this study because the project is interested in *how* members of the disability movement see self-advocacy, and interaction – agreements or disagreements, reflections etc. – during focus groups can create a richer and multi-layered understanding of the subject (Barbour, 2008; Cronin, 2013).

However, for pragmatic reasons, interviews were also employed in the study, with different but equally considerable advantages. Qualitative, semi-structured interviews are probably one of the most popular research methods (Gilbert, 2008). Interviews are found useful when exploring participants experiences, views or attitudes about issues. In this study, semi-structured interviews were employed because it was assumed that more participants can be

included in the study if they have the opportunity to be interviewed one-on-one instead of a group setting. For example, participants may choose to be interviewed because they value privacy and would not like to reveal their views in front of others. A number of personal issues may also motivate people to prefer interviews to focus groups. For instance, anxiety may prompt participants to prefer interviews to focus groups. Furthermore, some autistic self-advocates and self-advocates with a learning disability may prefer being interviewed with the provision of special adjustments such as low sensory stimuli environment or the use of easy-read materials and visual aids, which may be more available in a one-on-one setting. This study was done in a highly complex research environment, and it was important to include a diverse group of participants and not only those who are willing to or capable of expressing their view in a group setting. Therefore, all participants were offered the chance to be interviewed.

This approach was proven successful, because several participants, including autistic self-advocates, parents and some professional advocates agreed to participate under the condition that they are interviewed by the researcher instead of joining a focus group.

Interviews and focus groups are, of course far from being the same or even very similar to each other (Fielding & Thomas, 2013), and researchers must be careful when planning to use both methods within the same project (Fielding & Thomas, 2013; Gilbert, 2008). In the present study, both focus groups and interviews had the same interview guide (see Appendix 5.), which made the interview and focus group transcriptions relatively similar in their structures, including in the sequence of the topics discussed. The main method for analysis – thematic analysis – was also chosen because it allows for the inclusion of various texts, including transcripts from both qualitative interviews and focus groups (Cronin, 2013).

3.5.3 Why thematic analysis?

When looking at different groups within the disability movement (in this study: self-advocates, parents and professionals), in order to identify emerging patterns and relationships connecting these groups, it is highly important that diverse understandings remain relatable to one another. The diversity of understandings is even more prominent in this study, given that participant groups were composed of advocates and self-advocates from two countries, speaking about their views in two different languages. In fact, self-advocates and advocates coming from very diverse cultural, societal, or educational backgrounds shared their stories and feelings in a broad variety of personal styles, making it sometimes challenging to find emerging patterns.

Thematic analysis (Braun & Clarke, 2006) makes it possible to identify salient patterns, issues, problems etc. as *themes* emerging from the analysis of interview and focus group transcripts as texts. Thematic analysis is widely seen as a useful and flexible method for analysing textual data, especially in exploratory studies that look at new phenomena or studies that investigate previously known problems from a new direction (Gilbert, 2008). Thematic analysis – sometimes likened to a '*grounded theory lite*' (Braun & Clarke, 2006 p. 8) approach – is also known as being highly flexible in that it can be used in various ways depending on the objectives of the given study. For example, thematic analysis can be used for giving a rich thematic description to a larger dataset by which readers can get an overall understanding of dominant themes in the data. On the other hand, thematic analysis can also be used for giving a more nuanced and detailed description of one particular theme by relating it to a set of various subthemes and exploring relationships between 'families' of (sub)themes (Braun & Clarke, 2006). Both these characteristics – being able to capture larger patterns and to give more nuanced descriptions – were needed in the present exploratory study.

Thematic analysis gave real potential to the exploratory, inductive approach used in the project. For example, in some chapters, thematic analysis was used to give a detailed description of all participants' views, their underlying motivations, their practices or the way they perceive others and how these themes may relate to each other – while in other chapters attention was focused on one or two themes only.

3.6 DATA COLLECTION

Collecting data about disabled people's lives is challenging for every researcher. When inviting people to personal interviews and focus groups, the researcher must make sure that the conduct of the study is both ethical and professional, and participants' rights, privacy and freedom of choice are respected throughout the project.

3.6.1 Ethical considerations

Researching the lives of disabled people proposes a multitude of ethical problems (Goodley & Moore, 2000; Moore, Beazley, & Maelzer, 1998). Such issues include options to remain anonymous, informed consent, and the need for reasonable adjustments.

Ethics approval was acquired from the Tizard Ethics Committee in June 2016. All ethics materials such as information sheets, consent forms, and complaints forms, including easy-ready versions were written in English, then later translated into Hungarian by the researcher (see Appendices). It was ensured that all participants were aware of all the

necessary information about their project and whenever further explanation needed, the researcher was ready to answer participants' questions. Such questions were discussed before signing consent forms either by email or in person. This was especially needed with those participants who were interviewed many weeks after the first contact was made – here, the researcher resent materials and repeated initial introduction prior to the interview.

Participation was voluntary and anonymous. Reasonable adjustments were given to participants, for example, focus groups and interviews were organised at venues with low sensory stimuli. In some cases, the researcher consulted support workers to understand the communicational needs of self-advocates with a learning disability.

As an overwhelming majority of participants chose to remain anonymous, quotations from participants will be identified only by participant group and country of origin throughout the thesis.

3.6.2 Selection criteria

Sampling participants was done with particular attention to the background and experiences of advocates and self-advocates. Because the study employs an open approach to advocacy, with a broadly understood working definition of advocacy and self-advocacy explained before, invitations were sent to a diverse group of potential participants. It was important, that participants come from diverse backgrounds, and give voice to many different types of advocacy and self-advocacy people may do across the disability movement. Therefore, particular attention was paid to issues such as:

1. **Size and scope of organisation**s. It was crucial that participants come from very diverse organisational backgrounds and talk about views rooted in diverse experiences within different organisational structures and traditions. Advocates may work in official 'advocate' positions in the UK (under the Care Act), but such legal category is unknown in Hungary – thus, participants were invited even if they did not work officially as 'advocates', but did elements of advocacy in their job. For example, professional advocates who participated in the study had diverse backgrounds:
    o   A local charity in the UK that supports autistic people and their families to make their voices heard, informs them about their rights and helps them attend meetings or hearings.
    o   A local NGO in Hungary supporting autistic people and people with a learning disability to become independent – they run a social enterprise and organise cultural activities for people with a learning disability (and other disability groups).

59

o A known national umbrella NGO in Hungary that is active in human rights lobby and runs self-advocacy groups for people with a learning disability.

o A small disability rights watchdog in a Hungarian city, with a special focus on the rights of people with profound learning and/or physical disabilities.

o A small local self-advocacy organisation in the UK, controlled by self-advocates and non-disabled advocates.

o A service provider NGO in Hungary, with a popular, pro bono legal aid service in the learning disability field – they also run anti-stigma programmes and lobby for legal change.

o A national autism charity in the UK that employs hundreds of people and runs dozens of self-advocacy groups across the country.

o A local service provider for people with severe and multiple disabilities in Hungary, that has initiated and run a number of disability rights and advocacy programmes.

o A major British charity in learning disability that runs various advocacy initiatives.

It was hoped that the inclusion of participants with such varied personal and professional backgrounds would convey a broad set of views and experiences. For example, the views of those who work for big vs. small organisations; the views of those who work in autism or learning disability organisations (or both); the views of those at national level organisations concerned with broader issues vs. organisations that work with local communities; the views of those working at organisations with many employees vs. the views of those who work at small organisations.

2. **The diversity of personal experiences in advocacy/self-advocacy.** The study recognises the fact that while professional advocates may hold advocacy positions for several years, such direct and continuous engagement with parent-advocacy or self-advocacy may not be easily possible for others. People may join parent-groups or self-advocacy groups, and then they may leave those groups for some time, or become only 'loose' members to groups, for private reasons or because the group dissolves. Therefore, active membership in an advocacy group was not a requirement and participants were selected if they had significant experience in any form of advocacy/self-advocacy. The level of experience in advocacy varied among participants, many of them having over 15-20 years of experience (typically professionals and some parents). The majority of participants had three to ten years of experience (most self-advocates, some parents and professionals falling under this category). The shortest experience was three years in advocacy by two

professional advocates but both of them had held support worker or other relevant positions before they engaged with advocacy making their experience more profound.

3. The inclusion of individual self-advocates. While professional advocacy is almost always carried out in paid positions at organisations such as charities, NGOs, DPOs, human rights agencies etc, this is not always the case for parents and self-advocates. As seen in Chapter 2, self-advocacy (and advocacy in general) has a strong personal level and indeed, many people may consider themselves individual advocates or self-advocates, even if they do not have formal membership in a group or NGO. It was crucial that such individual experiences are present among participants, therefore it was explicitly stated in first contact messages that individual advocates and self-advocates can also join the study. Those who disclosed that they consider themselves individual self-advocates included, for example:

o A UK-based autistic self-advocate who has done various art performances over several years, using art as a form of expression about life history, identity, being autistic, neurodiversity, stigma etc.

o A British parent who has run an internet blog and has published several books and articles on severe learning disability.

o A Hungarian parent who advocates for his son with Down Syndrome – although he has official membership in a parent-organisation, he considers himself a solo parent-advocate.

o An autistic self-advocate in Britain who has run anti-stigma workshops in a church community but does not belong to a formal self-advocacy organisation.

o A parent who had held various positions in parent organisations in Hungary. At the time of data collection, she did not have membership in parent-groups.

o A Hungarian autistic self-advocate who participated in self-advocacy groups and has been working as a trainer for other self-advocates, but at the time of data collection identified as a '*self-advocate who doesn't belong to any organisation*'.

o An autistic person in Britain who is a freelance consultant and gives training courses on neurodiversity. Although she has engaged with various autistic communities, she identifies as working on her own capacity as an autistic expert.

To conclude, the main selection criteria for participants both in Hungary and in the UK was the existence of significant experience in advocacy or self-advocacy.

3.6.3 Recruitment of participants

Recruitment itself is known to be difficult in the disability field, for example, because participants may be reluctant to join, or because organisations or services are hesitant to

cooperate with researchers. In the present project, the recruitment process was also anticipated to be challenging. However, after the first round of invitation was sent out in September 2016, several participants and DPOs expressed their interest to join the study. It was the impression of the researcher that most participants in Hungary were decidedly happy to share their ideas about advocacy with a researcher – some participants even expressed this during interviews through statements such as 'more people should listen to us' and 'more studies are needed about advocacy'. In Hungary, both major national umbrella organisations were contacted, both of them representing families: Hungarian Autistic Society – AOSZ; Hungarian Association of Persons with Intellectual Disability – EFOESZ; but also other organisations were asked to support recruitment by circulating invitations. These organisations include the Hand in Hand Foundation (operating both in autism and learning disability); a small human rights NGO speaking for people with severe and multiple disabilities; an informal group of autistic self-advocates; and two more parent-run NGOs. Recruitment in Hungary started in September 2016 and data collection finished in December 2016.

In the UK, recruitment was somewhat more difficult, potentially due to the fact that British researchers regularly approach NGOs, services and charities in learning disability and autism to participate in research – some participants noted that they often get invitations to participate in studies. Recruitment in the UK started in November 2016 and data collection finished in May 2017.

In Britain, the recruitment of participants was done through existing contacts of the researcher and the Tizard Centre. Invitations were also sent with the help of organisations including Learning Disability England, Kent Autistic Trust, the National Autistic Society, Mencap, and a number of other local charities. Individual self-advocates and parent advocates were found through online searches. In both countries, particular attention was given to grassroots activists who may not have direct contact with well-known national umbrella charities or DPOs – some activists were approached at conferences or other public meetings. In both countries, recruited participants were asked to name further possible participants to ensure a broader pool. This 'snowball sampling' (Biernacki & Waldorf, 1981) was used successfully to recruit participants outside the researcher's and the Tizard Centre's networks.

Altogether 43 participants were interviewed in four focus groups and 24 interviews. The breakdown of participant groups (Table 3.2) shows that the number of people in each of the groups was relatively even. Groups slightly overlapped, for example, there were two self-

advocates with learning disabilities who were also autistic, however, both of them participated in organisations operating in learning disability. Also, some parents and professionals advocated for both autistic people and people with a learning disability. These overlaps will be discussed in Chapter 4 and Chapter 5 to a greater extent.

Participants	United Kingdom	Hungary	Total
Self-advocates with a learning disability	4 interviews (including 1 group interview, n=2)	1 focus group (n=3) + 1 interview = 4 participants	8
Autistic self-advocates	5 interviews	1 focus group (n=4) + 2 interviews = 6 participants	11
Advocates working in learning disability	5 interviews	1 focus group (n=5) + 4 interviews = 9 participants	14
Advocates for autistic people	5 interviews	1 focus group (n=4) + 1 interview = 5 participants	10
TOTAL	Total in the UK: N=19 participants	Total in Hungary: N= 24 participants	**N= 43 participants**

Table 3.2 Participants

3.6.4 Conducting interviews and focus groups

The project was designed to employ both interviews and focus groups as it was anticipated that some participants would be reluctant to join group discussions for personal reasons or preferences, for example for being concerned about confidentiality. Thus, at the time of the initial contact, the invitation offered options to participate either in a focus group or in an interview. This opportunity was taken by several participants who felt anxious about talking in front of others but wanted to share their thoughts. Geographic distance also made it necessary to interview people separately, for example, this was the case in England where participants lived often far from each other and found it too costly and time-consuming to travel to a focus group.

Focus groups took place at DPO premises, and interviews were conducted at venues that best suited the preferences of participants, e.g. their offices, or quiet places such as cafes or library premises. Few interviews were also conducted at the University of Kent. For participants with sensory or other (e.g. anxiety) issues, special arrangements were made to answer their special needs, for example, Skype-interviews were arranged.

Measures were taken to offer and provide reasonable adjustments to participants. At the time of the first contact, the researcher offered each participant the possibility of conducting the interview on Skype or by phone or joining a focus group by Skype. This offer was made to ensure that participants' special needs are met, for example, because it is known that

participants may find group discussions or research interviews stressful (Barbour, 2008; Fielding & Thomas, 2013). Indeed, some participants expressed their preferences to be interviewed by phone or to join focus groups by Skype. Two professional advocates in the UK also chose to be interviewed by Skype/phone, because geographic distance made it difficult to meet the researcher in person.

Most interviews and focus groups were conducted in Budapest, and at various locations in Kent or in London. However, participants' geographic origin was more diverse: participants were doing advocacy in different regions both in the UK (Wales, Yorkshire, Hertfordshire, Northern-Ireland, London, and different parts of the South East) and also in Hungary (most participants worked in Budapest, but others came from Eastern and Western Hungary, for example, Zala county, Debrecen, Miskolc, and Tata). The geographic diversity and the fact that several participants have been doing advocacy work on a national or regional level provided rich data regarding advocacy practices in different rural and urban contexts.

The length of interviews and focus groups varied: interviews ranged between 35 to 95 minutes in length, focus groups were between 65 to 95 minutes. [15]

3.7 DATA ANALYSIS

For the data analysis, all interview and focus group recordings were transcribed by the researcher in MS Word. Transcriptions followed a verbatim transcription tradition by marking emotive reactions in the text such as 'wow!' or '[laughter]' or '[pause]' – these were retained in quotes used in the final report. These not only give extra detail and colour to quotations themselves, but they also contribute to the better understanding of participants' stance about issues they feel explicitly emotional about. Transcribing was done in English for participants interviewed in the UK and in Hungarian for Hungarian participants. All transcribing was done by the researcher between June and August 2017.

Coding of data was carried out by using NVIVO software – the researcher read all the transcripts several times and created codes (nodes and sub-nodes) in the software. These nodes were grouped, creating altogether 24 themes and several subthemes. In this inductive approach, the researcher relied largely on data itself when creating various themes emerging from the overall dataset, and previous theories did not inform strongly the coding of data.

---

[15] Before and after interviews and focus groups, the researcher also took fieldnotes in written format but sometimes recorded on Dictaphone. These fieldnotes included observations about various issues, for example, impressions based on non-recorded conversations (with a co-worker at a DPO or what participants said before and after interviews) as well as some other thoughts prompted by the interview.

In other words: during coding, the researcher looked at what participants said and themes were not established to verify or refute one particular theory or the findings of any previous study in literature. Of course, since the view of participants were, in fact, answers to questions listed up in the interview guide, the coding did not happen in a full 'epistemological vacuum'. The researcher used the interview and focus group themes only as reference points but looked at emerging themes mostly outside issues proposed in interview questions. Therefore, the coding resulted in a long list of themes and subthemes which constituted the basis for all the data analysed and presented throughout this thesis.

Analysis, however, was not complete after this first full thematic analysis of the text. As the project rolled out and several stages of the study identified emerging issues, the researcher once again 'went back' to the original transcripts to further analyse them, this time with a particular question or problem in mind. Some themes, therefore, were created at later stages of the project, only after some previous analyses prompted the researcher to propose new questions. Consequently, secondary research questions aiding thorough analysis, along with relevant methodological decisions will be presented at the beginning of later chapters.

Thematic analysis was carried out on both English and Hungarian texts. Codes and themes created in NVIVO are stored in English, although quotes under themes may be both in English and in Hungarian. Translation of Hungarian quotes by participants into English was carried out only at the final stage, during the write-up of the doctoral thesis and/or articles. Translation from Hungarian transcriptions into English once again was done by the researcher. Where relevant, the original Hungarian terms are marked in the text, for example, to demonstrate the variability of terminology specific to the context.

<p align="center">***</p>

In the following chapter, the project will look at conceptualisations of self-advocacy, based on participants' accounts, because literature review showed important current changes in the disability movement which may also influence how 'self-advocacy' is understood by members of the movement. Therefore, Chapter 4 will be devoted to an analysis of contemporary concepts of self-advocacy. In the face of findings, the chapter will also attempt to rethink the current definition self-advocacy.

4   CHAPTER FOUR – CONCEPTUALISING SELF-ADVOCACY

THE CHANGING LANDSCAPE OF SELF-ADVOCACY

As argued in Chapter 2, disability advocacy and self-advocacy can be seen operating on three different levels. Self-advocacy is always personal, where one 'speaks up for oneself'. Self-advocates also often work in groups or organisations, thereby establishing a collective voice. On the third, societal level there is a widely recognised 'self-advocacy movement' which is composed of different self-advocacy organisations, disabled people's organisations and their allies.

Chapter 2 also argued that advocacy and self-advocacy have had various constructions throughout history (Buchanan & Walmsley, 2006; Bylov, 2006) and definitions continue to change – in fact, any definitions of advocacy are understood in relation to cultural, historical and other factors. Also, members of the disability advocacy movement have various views on what it means to be belonging to the disability movement (Beckett, 2006; Shakespeare, 1993). Therefore, in order to understand self-advocates' position within the broader disability movement, it is necessary to examine what self-advocacy and advocacy mean to members of the disability movement today. There are four important areas where changes can be observed.

Can we clearly define self vs organisational advocacy?

Firstly, self-advocacy has grown and changed in complexity over recent years. In the literature review, individual, organisational and social movement levels were introduced, but it was also noted that recently developed forms of (self-)advocacy increasingly resist categorisation. For example, self-advocates may be active in one formal organisation as members or even as organisational leaders, but they may also be speaking about their individual experiences in authored books or personal websites – such books and personal websites have become numerous since the 2000s. Which part of the work of such a self-advocate is individual and which part is organisational? When are they 'working' as advocates for others or peer-advocates and when are they speaking up about their own demands?

In another example: individual self-advocates may submit open letters or start petitions that are signed or supported by others such as self-advocates and non-disabled advocates or supporters. Such initiatives sometimes get broad recognition throughout media or influence the law (Orsini & Smith, 2010), thereby establishing collective action against oppression and

bypassing formal advocacy organisations' lobby work. Would such an open letter be individual or collective struggle? Do these new forms of collective (self-)organisation influence the way formal organisations work?

Furthermore, high-level positions in charities or public bodies have become available to self-advocates in recent years. Today, self-advocates may be elected to become members of UN Committees (Inclusion International, 2016), trustees of charities or DPOs (ÉFOÉSZ, 2016a; EPSA, 2017) or even to work as city councillors, thereby 'speaking up' for others with learning disabilities or autism or even for non-disabled people in the public sphere. Does a self-advocate holding a public office or trusteeship at an NGO become a professional advocate for disability rights? Where is the line between these public office-holders' own self-advocacy and their professional work?

Even if a common feature such as 'speaking up for oneself' can be recognised across the above examples, it still remains an open question what constitutes self-advocacy within such largely different and increasingly complex contexts.

Who represents whom?

Secondly, the question of representation – 'who represents whom?' – has become central to the whole of disability advocacy since the ratification of the UN CRPD in 2007. In one of its core provisions, Article 33 and Article 4 of the CRPD make it mandatory for States Parties to consult and cooperate with persons with disabilities and their 'representative organisations' (UN General Assembly, 2007).

> *Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process.* (CRPD Article 33(3))

> *In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.* (CRPD Article 4(3))

This strong emphasis on representation proposes a problem for those attempting to define self-advocacy within the complicated system of various DPOs, charities, formal and informal groups of self-advocates, and mixed organisations, mostly because it is often unclear when self-advocates are speaking for themselves and when they speak 'on behalf' of other (or 'all')

self-advocates. Taking the previous example of an autistic board member of a charity: is this person self-advocating every time when they speak at a board meeting? Or are they representing other self-advocates? Can self-advocate board members represent parents as well, thereby becoming their advocates? Should human rights mechanisms or state policies recognise such 'mixed' organisations, jointly led by parents and self-advocates, or should they only embrace organisations led exclusively by self-advocates as representative voices? Such questions around representation make us reconsider and go beyond traditional definitions of self-advocacy.

Changing patterns of interaction

Thirdly, broader societal changes impact the way potential or practising self-advocates and advocates interact with each other or the public – resulting in a dynamically evolving system of contemporary disability advocacy. Goodley stated already in 2000 in his pivotal book that self-advocacy '*means so much to so many and has grown in complexity*' (p. 6), and in the 2010s even more complex and novel forms of self-advocacy are appearing.

Today, widespread internet connectivity and mobile phone ownership allow disability advocates to connect with each other and with non-disabled people in a myriad of ways, resulting in increased connectedness, and new opportunities to organise social protests (Pearson & Trevisan, 2015; Trevisan, 2016). Smartphone applications, video chat software, various chatbots, social media etc. all allow for instant and often anonymised communication between people, making geographical distance irrelevant. Can these forms of self-organisation and social networking be categorised as individual self-advocacy or are they more organisational? Is it appropriate to call online collectives (chat rooms, Facebook-groups or email lists) of autistic people an 'organisation' or should disability scholars and activists update their vocabulary and open a new chapter for virtual communities? How do online activities relate to offline self-advocacy? How much have disability advocacy and self-advocacy changed by the impact of the 'mediatised society' (Couldry, 2012)?

Visibility in the media

Finally, there is also a growing visibility of disabled people, including self-advocates across the media (Ellis & Goggin, 2015), including on social media (Ellis, Goggin, Huntsinger, & Senft, 2014). Disabled people, including autistic people and people with a learning disability, have become producers of media content. A new, vocal, and lively autistic community is making its voice heard through the internet – sometimes with the help of formal advocacy organisations, but often also outside these organisations (McGuire, 2016). This is partly due

to the increasing prevalence of autism spectrum conditions which means that more and more people on the internet identify as autistic.

The growing visibility of autism on the world wide web is not at all surprising. Society as a whole has also changed its approach to consuming and producing media (Couldry, 2012), so autistic people are only doing what many other people are doing in postmodern societies: they are documenting their lives and making demands in the global online space by posting blog posts, photos, memes, art, videos, entering debates or starting petitions.

At the same time, new online autism (and sometimes learning disability) contents confront us with new questions. For example, the real identities of bloggers and vloggers sometimes remain unknown to the public. In fact, anonymity may be one of the advantages of online activities as opposed to offline, more traditional networking (Benford & Standen, 2009). Is it legitimate to see such – perhaps anonymous – individual voices as representative to their peers or as legitimate claims at all? Are these new forms of online activism making an impact on how we see offline self-advocacy? Do online autistic activists (or less often: people with a learning disability) see themselves as self-advocates at all or are they just doing what many other people are doing on social media?

Answering all of these questions cannot be the aim of the present study. However, such dilemmas show the challenge when trying to define contemporary advocacy and self-advocacy. In fact, contemporary changes in disability advocacy make it necessary to revisit previous concepts of advocacy.

In this chapter, concepts of advocacy and self-advocacy will be asserted, based on participants' views. To assess how members of the contemporary learning disability and autism advocacy movement conceptualise advocacy and self-advocacy, two different approaches will be taken. First, based on participants' views, definitions of advocacy and self-advocacy will be appraised. Later, to amend findings of the first analysis, but also to offer a new way of conceptualising advocacy and self-advocacy, a practice-based analysis will be offered.

4.1   FIRST ANALYSIS: Definitions of advocacy and self-advocacy

In this section, in order to appraise advocates' and self-advocates' conceptualisation of advocacy and self-advocacy, definitions of advocacy/self-advocacy will be assessed.

Methodology

The analysis will be based on answers provided by participants when they were asked about definitions of advocacy and self-advocacy. Definitions will be analysed to identify common themes that may expose shared features of different conceptualisations. For the identification of common themes, thematic analysis will be used.

During interviews and focus groups, all participants were asked one or two of the following questions: what is advocacy? How would you define it? What is self-advocacy? Are they similar or are they different? These questions encouraged participants to define what advocacy and self-advocacy meant for them, and what they thought would be general definitions. In most discussions, people explained their definition of both advocacy and self-advocacy by putting them into the context of general disability advocacy. Therefore, statements provided definitions for both 'advocacy', 'self-advocacy' and even for other terms, depending on the participants' own experiences. Other terms used by participants included 'peer support' or 'peer advocacy', 'parent advocacy', 'professional advocacy', 'human rights advocacy', 'protecting rights', 'autistic advocacy' and 'activism' were all mentioned, giving an even richer understanding of the different ways advocacy operates.

For the analysis of data, thematic analysis was employed with the help of NVIVO software. For the thematic analysis, only interviews where participants answered questions about definitions were analysed (n=40). Definitions were sometimes found not only in answers given directly to the proposed question about definitions but across the same interview or focus group, when participants came back to the issue of definition at a later stage of the interview, for example making a reference back to their earlier views. Therefore, in many cases, not only one but several, mutually complementary answers by the same participant were identified. Notably, not all participants answered the questions, because some of them either refused to answer, ignored the question (for example in a focus group), or in one case said they did not know how to define advocacy.

4.1.1 Reflections on language – Erratic terminology

The initial aim of this analysis was to explore whether there was any agreement in terms of how advocacy was conceptualised. However, repeated readings of the transcribed data revealed that there were critical differences in the terminology participants use.[16] Therefore, although the initial aim of the question about definitions was to explore the concepts

---

[16] These differences in terminology were not related to the differences between English and Hungarian terms as both 'advocacy' and 'self-advocacy' have Hungarian translations that participants widely recognised and used 'érdekvédelem' and 'önérvényesítés', respectively.

participants employ to define advocacy and self-advocacy, a linguistic problem was identified that hindered straightforward thematic analysis: participants used various different terms to explain their understanding of advocacy and self-advocacy, and there was a lack of consensus between participants about the meanings of different terms.

In the next section, these terms will be analysed by assessing them on two levels: first by looking at words that were used as synonyms of advocacy or self-advocacy; then different meanings attributed to the words *'advocacy'* / *'érdekvédelem'* and *'self-advocacy'* / *'önérvényesítés'* will be assessed. The analysis will be carried out both on the *lexical level* – what terms or word forms are used as synonyms to advocacy and self-advocacy –, and also on the *semantic level* – what meanings people attribute to the two terms 'advocacy' and 'self-advocacy'.

In the following analysis, a distinction will be made between meanings and definitions. *Meanings* will be looked at in a linguistic context to seek common relationships between signifiers ('advocacy' and 'self-advocacy') and their meanings, based on participants' use of the two words. On the other hand, *definitions* will be understood to be a broader category which includes both the meaning of the words and also the conceptualisation of the phenomena of advocacy and self-advocacy, for example how participants see themselves or others practising advocacy, what legal definitions or cultural concepts they apply to advocacy and self-advocacy etc.

In the following section, terminology will be appraised by looking at (i) multiple terms, (ii) confronting meanings, and (iii) subjective definitions.

4.1.1.1 Multiple terms

Analysis revealed that participants used a wide array of terms as synonyms of '*self-advocacy*' and '*advocacy*' which makes it difficult to pin down agreed-upon definitions of the two terms. Beyond talking about what was generally understood to be 'advocacy' and 'self-advocacy', participants often spoke about certain specific types of advocacy or self-advocacy, marked by synonymous words. Both in English and in Hungarian, several such synonyms were mentioned by participants (see Table 4.1).

Terms in English	Terms in Hungarian [with English translations]
Advocacy	**Érdekvédelem ['advocacy']**
Self-advocacy	**Önérvényesítés ['self-advocacy']**
Self-determination	Önérdekérvényesítés
Lobby	['self-determination', generally used as a
Experts by experience (to describe self-advocates)	synonym to self-advocacy]
	Lobbi ['Lobby']
Parent advocacy	Tapasztalati szakértő ['expert by experience']
Autists (to describe autistic people who advocate)	Szülői érdekvédelem ['parent advocacy']
Peer advocacy	Jogvédelem ['Rights-protection']
Professional advocacy	Érdekérvényesítés ['representation of one's
Activism	interest', generally used as a synonym to
	advocacy]
	Aktivista ['activist']

Table 4.1 Examples for terms mentioned by participants as synonyms of advocacy / self-advocacy

Terms in the two languages largely overlapped, for example common terms in English such as *'advocacy'*, *'self-advocacy'*, *'activist'*, *'parent advocate'*, *'lobby'*, *'self-determination'*, *'experts by experience'* are used and known equally both in English and – in their Hungarian translations – in Hungarian. Differences also exist: while in Hungarian *'jogvédelem'* ['rights-protection'] is a widely used term to describe legal or human rights advocacy, but no similar term was provided by British participants (although human rights were discussed as relevant in the context of advocacy). On the other hand, while *'professional advocacy'* is commonly used and has a specific meaning in Britain under the Care Act 2014, no similar, legally recognised profession exists in Hungary, despite the fact that people may hold paid positions which may be categorised as advocacy.

Terms used to describe advocacy and self-advocacy varied between participants, sometimes even between those who worked together regularly (in two Hungarian focus groups). For example, in a focus group in Hungary, four experienced advocates – parents of autistic children who also worked at advocacy organisations – had a lively debate about different terms. In the following dialogue, different terms used for advocacy and self-advocacy will be highlighted in bold to demonstrate the diversity of the vocabulary advocates use when defining advocacy. The dialogue also shows that terminology used by participants is highly erratic.

> *Researcher: How would you define advocacy?*
>
> *Advocate 1: Well, **advocacy** can mean so many things, starting from supporting parents up to national **advocacy** and **lobby work**. The spectrum here is very broad, depending on what we call **advocacy**.*

*Advocate 2: Yes, and actually I think everyone does **advocacy** to a certain extent because everyone is doing it! It is **advocacy** when I go into my child's school and speak with the teacher to make sure that he feels better in class, then it is also **advocacy** when I read laws and policies and then write up **lobby** materials, and also when I work in our local NGO and try to improve things locally, in local services. Or even when I work to bring local parents together so we can look at things and see what we can do together to improve things...*

*Advocate 3: I think there needs to be a common ground, a disadvantage which is a given for us and also for our children, and then either with them, standing behind them or on behalf of them we **speak up** and that's already **advocacy**... And then, just as you said, **advocacy** has different levels, because when I only fight for my own child it is more like **self-representation**, but if I do it in a group and I try to change things for others as well, then it's **advocacy**.*

*Advocate 2: ...yes, it is important to define things, because we use different words, **self-representation**, **self-determination** and **advocacy**, and all these have slightly different meanings.*

*Advocate 4: My understanding is that when a parent **fights** only for their one child, they are more like 'mother tigers', which is different.*

*Advocate 2: But it is still **advocacy** if you do it on your own...!*

*Advocate 3: ...I think it's more like **self-representation**.*

*Advocate 4: ... What I am saying is that when in 2014 I started [advocacy] then I was already not only a parent but also an **advocate**... this was when we established the organisation. The two roles need different strategies.*

*Advocate 2: I still think these are just different levels, like the individual, local or national, but that's not so much... Of course, there is both **individual advocacy** and **self-representation**, because when I go into my son's school and show the principal the Education Act and say 'hello, can you see this?' so then that's gonna help others, too...*

*Advocate 3: Yes, it is **self-representation** if you go into the school but if you fight with the local council to open a new unit for autistic children in the local school, that's when it becomes **advocacy**.*

(Hungarian advocates in autism, emphasis added)

The above dialogue demonstrates that participants make a distinction between various forms of advocacy and they suggest that different terms can be applied to different types of advocacy. This is a linguistic problem on the *lexical level* that needs to be considered when

73

attempting to analyse conceptualisations of advocacy: not all forms of advocacy and self-advocacy are called 'advocacy' or 'self-advocacy' by members of the disability movement. For example, one autistic self-advocate from Britain called herself an *'accidental activist'* while raising concerns about the use of the terms *'self-advocacy'*. Therefore, any conceptualisation of self-advocacy must recognise the fluidity of language. Members of the disability movement may often talk about advocacy and self-advocacy while not using the terms 'advocacy' and 'self-advocacy'. Importantly, when people use synonyms of the two terms, such synonyms may have no consensual meaning within the movement.

4.1.1.2   Confronting meanings

Not only synonyms but also both words central to this inquiry, *'advocacy'* and *'self-advocacy'* have various meanings attributed to them by participants. In fact, participants provided different, often confronting meanings to these two words.

First, the meaning of the word *'self-advocacy'* is not at all consensual. Although, as seen in Chapter 2 *'self-advocacy'* is widely used for disabled people advocating for themselves, participants in this study provided altered meanings. For example, according to a Hungarian advocate with over 15 years of experience in supporting self-advocates with a learning disability, 'self-advocacy' is not at all specific to disabled people but it is done by everyone.

> *'I think everyone is doing self-advocacy! Simply put, we all self-advocate, and you don't have to have a cognitive disability for this. You need information to make your decisions, to stand up for yourself (...) in a given area of life, private life or in the office. An everyday thing*.'

The above view is reasserted by a British advocate for autistic people who stated '*how do you define self-advocacy (…) Well, I suppose everyone does it to a certain extent, I mean people are always getting their views across to some extent. So, I suppose everyone does it individually*.' Another long-term human rights advocate for people with severe and multiple disabilities in Hungary confirmed this opinion *'self-advocacy is when people recognise that they are being oppressed and they say „hang on, this cannot go on"!'* – thereby extending the definition of self-advocacy to anyone who speaks up as member of an oppressed group.

It is not only the term *'self-advocacy'* that can include non-disabled people who advocate for themselves, but the word *'advocacy'* is also inclusive of disabled people who speak up for themselves:

'Anybody can speak up about their needs, that's advocacy when they express and represent these interests in any instances of their lives. And I think this applies to just about anyone, so even to someone with a cognitive impairment…, so when they can express their interests and their needs, and stand up for these, that is advocacy.' *(Hungarian advocate for people with a learning disability)*

This view was repeated by an autistic self-advocate in Hungary, who stated *'everyone is doing their own advocacy within the limits of their own individualism'.*

Similar views were expressed by several other participants as well. Furthermore, the use of the words 'advocate' or 'self-advocate' was not even necessary for doing advocacy or self-advocacy. Several autistic self-advocates in this study stated that they rarely called themselves publicly 'self-advocates'. Notably, some autistic participants sometimes call themselves 'advocates' and not 'self-advocates'. For example, one British autistic participant who was invited to the study in her capacity as an autistic self-advocate featured the following signature in her emails *'X.Y.,* **autism advocate** *and trainer'* (emphasis added). Other participants highlighted the inclusive nature of the concept of advocacy.

> *I don't know if I would necessarily call myself an* **advocate** *but people started to call me this.* (UK autistic self-advocate, emphasis added)

A similar understanding was found in the statement of other participants. Another Britain-based autistic self-advocate who accepted the invitation to participate in this study, and talked extensively about her self-advocacy, noted: *'when I was coming over to talk to you I was thinking "do I really call myself a self-advocate?"'.*

The problem with defining advocacy or self-advocacy in the linguistic level is even more apparent in the following opinion. One autistic self-advocate expressed her strong opposition to the term 'self-advocate', because it is not specific enough to the autistic identity of people who do it, compared to, for example, feminists who do not need to be calling themselves advocates because their label ('feminist') succinctly signals what they do (i.e. being 'women self-advocates'). Notably, not only the meaning of the term but also its lexical use is debated.

> *Researcher: Do you think advocacy has a definition? Or does self-advocacy have one?*
> *Self-advocate: No, I mean no. I suppose 'self-advocacy' is not so bad, it's just sort of….*
> *I don't know, I got used to it now. When I first heard of it, at the time I didn't like it.*
> *(…) Especially [by] the general public, but when there are organisations such as the*
> *NAS [National Autistic Society], it really should know better, it really hacks me off. (…)*

I suppose there's nobody who talks about "female women self-advocates" for God's sake! You know, you're a feminist! But as there is a language, a feminist equivalent for autistic self-advocates, well there's no better word, we have to stick with autistic self-advocates, I mean some people use the word "autists" but this is more like just to mean 'autistic people' and not really the equivalent to "feminists". (British autistic self-advocate)

Indeed, the term 'self-advocacy' without a preceding adjective does not signal what kind of self-advocacy one does. For example, the term self-advocacy is similarly used in the context of healthcare for patients in general (Brashers, Haas, & Neidig, 1999), or in the context of certain health conditions such as human immunodeficiency virus - HIV (Brashers, Haas, Neidig, & Rintamaki, 2002) or cancer (Hagan & Donovan, 2013).

Furthermore, there were also participants who strongly oppose or avoid using these terms because of various individual oppositions to their meanings. For example, one participant refused to call herself an advocate although she acknowledged what she did was advocacy.

I never say I am an advocate, which has a particular meaning. Which doesn't really get… my role is to support parents to say what they want to say really but sometimes I might be speaking for them when they ask me to. (…) I have done advocacy training and at the end of it, I decided I wasn't an advocate because it was more to do with speaking for someone rather than helping them to speak for themselves and I know there are lots of definitions but the training that I did convinced me that wasn't my role. But in general terms, I AM AN ADVOCATE [raises voice], just not in legal terms, not in formal terms. (UK advocate for autistic people)

The above examples demonstrate that members of the learning disability and autism advocacy movement often disagree about the meaning of the words 'advocacy' or 'self-advocacy'. 'Advocacy' may mean roles traditionally understood being 'self-advocacy'; 'self-advocacy' may also include advocacy done by non-disabled people. This semantic problem signals that establishing one common concept of advocacy and self-advocacy may be impossible because the two words do not necessarily have consensual meanings between members of the disability movement. Indeed, the practical use of the word, based on participants' views is more erratic than previous studies suggest.

However, not only terminological and semantic differences were found. The definitions/conceptualisation of the two, most widely acknowledged words 'advocacy' and 'self-advocacy' also differed among participants.

76

4.1.1.3   All definitions are subjective

Participants provided various different definitions to the two words. Professional advocates sometimes explained 'official' definitions that their jobs included, for example, British community advocates who worked under the Care Act 2014, or family support workers whose job included elements of advocacy, both having legally recognised definitions for advocacy. For them, the definition of 'advocacy' is largely codified by law. However, even those who were in paid employment as advocates acknowledged that advocacy may have many different forms and definitions outside their job descriptions.

Definitions provided by other participants such as parents or self-advocates were very diverse. In fact, several participants recognised that there is not one singularly accepted meaning of the terms 'advocacy' or 'self-advocacy', because they take many different forms in practice. For instance, a Hungarian parent with over 10 years of experience in autism advocacy gave a detailed and well-informed definition:

> *You can certainly define advocacy. It has different levels. It is personal advocacy when I am only advocating for my own child. Then there is local advocacy when for example I meet with five other mothers who couldn't put their children in the local school and there I start to speak on behalf of them and advocate for them. This can be upgraded to a national or European level as well, but the aim is always the same: there is a group of people with a similar situation, in our case that's the autism of our children. (Hungarian advocate in autism)*

The broad range of activities or concepts advocacy and self-advocacy can include was also acknowledged by many other participants, for example, one autistic self-advocate in Hungary said: *'Advocacy is just a spectrum as well, we can speak up on every level of life, in small things and about laws or legislation as well.'* Similarly, several parent-advocates acknowledged that advocacy was difficult to define because it can take numerous different forms, for example, a Hungarian parent stated (already quoted before): *'… advocacy can mean so many things, starting from supporting parents up to national advocacy and lobby work. The spectrum here is very broad, depending on what we call advocacy*.'

Others saw no commonly agreed definition to advocacy or self-advocacy at all, with one British autistic self-advocate proclaiming *'Well, yeah, I don't think it [self-advocacy] does [have a definition]!'* Furthermore, numerous participants openly accepted that instead of one common definition there may only be only individual or personal definitions used by individuals.

77

It is the simplest form of it [advocacy] when someone tries to understand why they are autistic, read about it, and then reach out... That's my understanding anyway, but there are many other definitions, too. (Hungarian autistic self-advocate)

Another person also acknowledged the elusiveness of the definition and recalled changes in their idea of what advocacy means – thereby suggesting that subjective definitions, advocates' views may even change over time.

I got a clearer idea of what I mean by advocacy, I don't know if it always corresponds to other people's definitions. (…) I think advocacy is one of those things that can mean just about anything. (UK autistic self-advocate)

The subjectivity of the definition of advocacy or self-advocacy was openly stated by another autistic participant, who said when she 'does things' she may be advocating, but the knowledge to decide whether an action is advocacy or not is not available to her. The following statement suggests that reflective insight is not always available to people to define when they are (self-)advocating and when they are not.[17]

Researcher: If you had to explain what advocacy is, what would you say?
Self-advocate: I find that question very hard because my lived experience is basically being… I just step up and do things and a lot of the time I don't have the reflective knowledge to say that this is me doing advocacy or that is what that concept means. (UK autistic self-advocate)

Not only self-advocates noted the subjectivity of concepts. For example, one Hungarian professional advocate – an experienced support person to self-advocacy groups in learning disability – stated *'everyone has their own definition'*.

The subjectivity of concepts employed by participants exposes the difficulty to find one common and shared definition. It can be assumed that official definitions such as those stated in job descriptions, organisational manifestos or academic articles co-exist with highly individualised notions of advocacy and self-advocacy.

The three problems about the definitions of 'advocacy' and 'self-advocacy' – erratic terminology, confronting meanings and subjective definitions – pose serious limitations before any attempt to establish a common concept acceptable for all members of the learning disability and autism advocacy movement. It seems that language itself is a barrier

---

[17] The relationship between practice and knowledge in the context of advocacy will be revisited in the second, practice-theory inspired analysis in this chapter.

as it makes it difficult to see what advocacy and self-advocacy are in today's disability movement. Language can be misleading as it conflates and hides a multitude of different meanings and personal experiences of disabled people and their everyday activism. It is possible that conceptualisations of self-advocacy need to look beyond language and what people say about (self-)advocacy and find new analytical frames for their inquiry.

At the same time, not only the differences were emphasised by participants. There were also numerous similarities in the definitions provided. Before attempting to reconceptualise self-advocacy in the last part of this chapter, in the following section, such similarities and emerging themes will be identified.

4.1.2 Common themes in concepts of advocacy and self-advocacy

Despite the inconsistency in the terminology, meanings and definitions of advocacy and self-advocacy, participants' concepts also shared common features. In order to identify these common features or common themes, thematic analysis was carried out: all definitions were analysed and coded in NVIVO.

Three themes emerged as present in definitions. These themes – to be presented below – are central to participants' concepts and they signal that despite erratic terminology, confronting meanings and highly subjective definitions, there are also common properties members of the disabled people's movement attribute to advocacy or self-advocacy. The following themes are applicable to both of the two terms ('advocacy' and 'self-advocacy'), therefore they provide information on both how disabled and how non-disabled advocates see advocacy.

Theme 1: Speaking up

When asked about advocacy and self-advocacy, all participants noted that both terms signal someone's efforts to 'speak up' or 'speak up for others'. In fact, 'speaking up' – consistently with previous research presented in Chapter 2 – is a central theme to definitions used by participants. 'Speaking up' seems to be the 'connective tissue' between different types of advocacy, including local, national or international advocacy, self-advocacy, individual or collective forms of advocacy and self-advocacy, professional advocacy, and human rights advocacy etc.

However, participants also noted differences, mostly grouped around the question of 'who speaks up for whom'. Although – as noted before – several autistic self-advocates called themselves simply 'advocates' or questioned the adequacy and clarity of the term 'self-advocacy', nearly all participants, including parents, professional advocates, autistic people

79

and participants with a learning disability acknowledged fundamental differences that distinguish speaking up in self-advocacy from speaking up in other forms of advocacy. The following opinion demonstrates that it does matter who speaks for whom.

> *Researcher: What is advocacy?*
>
> *Advocate: I suppose it's just standing up for rights and equality!*
>
> *R: And what is self-advocacy?*
>
> *A: That's the person WITH DISABILITY [with emphasis] doing advocacy and speaking up.*
>
> *R: And what are the differences between the two?*
>
> *A: Well, disability advocacy includes people who may not have a disability themselves but who believe in rights and equality and are advocates. So, somebody like myself.*
>
> (UK advocate for people with a learning disability)

Most participants shared another common view that self-advocacy has a core element: self-representation, whereas advocacy usually covers some type of support to people. According to one British advocate for autistic people '*self-advocacy would be really them [autistic people] speaking on their own behalves'* – a view that was shared by many other participants, for example a Hungarian self-advocate with a learning disability who stated '*self-advocacy is basically that you can speak up for yourself and speak up for someone else, too.'* In this view, self-advocacy can include forms of peer-advocacy, when people speak up for others.

Furthermore, several advocates claimed that the ultimate aim of advocacy is to support people so they become able to speak up for themselves, thereby seeing a causative relationship between 'speaking up for someone' and 'speaking up for oneself'. The following opinion demonstrates that speaking up for others includes practices that make it possible for the supported people to speak up for themselves.

> *For us, this is the pinnacle of advocacy, when you are able to push or to speak up in the system so whenever we work with someone in any context, the aim is to enable them to be able to self-advocate.* (UK advocate for autistic people)

At the same time, speaking up for or on behalf of someone carries risks as well: several participants emphasised that it must be made clear whether someone is advocating for themselves or for others.

> *I think one of the risks with advocacy is you have to be very clear as to whether you are speaking for yourself.* (UK advocate for autistic people)

Many disabled participants agreed with this view. In fact, they made explicit, sometimes emotional statements about the differences between self-advocacy and advocacy done by others, with a consensual opinion that the voice of disabled people in their own advocacy is distinctly different from that of non-disabled advocates.

> *I think when someone speaks up for us, it is not our opinion. Maybe they are trying to give voice to our opinion, but not the way we want. Because they also mix in their own thoughts into what they are saying. It's just not our voice.* (Hungarian self-advocate with a learning disability)

Another Hungarian self-advocate with a learning disability stressed their own mixed emotions about advocates speaking up for self-advocates: '*I don't like when others speak up for me. I like to do it myself because I can advocate for myself.*' Autistic self-advocates expressed similar views, with one of them stating that human rights advocates may '*breach the independence*' of self-advocates when they try to advocate for them:

> *There is a difference, between [human] rights advocates and disabled people. When others like human rights advocates are trying to advocate for us then sometimes they are not exactly helping us to become independent. Our independence can be breached.* (Hungarian autistic self-advocate)

On the other hand, speaking up for someone else is not only a practice professional advocates or parent advocates do. According to a British self-advocate with a learning disability, speaking up for his peers is a core element of his self-advocacy.

> *Self-advocacy is a network like basically speaking up for your rights in society. So basically, as I am a self-advocate, I speak up for all the self-advocates in the United Kingdom. (UK self-advocate with a learning disability)*

Speaking up is a central theme in concepts of advocacy and self-advocacy for all participants, including professional advocates, self-advocates and parent advocates. This finding is consistent with the consensus in previous literature that advocacy and self-advocacy are in fact about 'speaking up' or 'standing up' against oppression.

Theme 2: Sharing information

There was another common theme in definitions: most participants put a particular emphasis on *sharing information* as a tool to advocate or self-advocate. For example, telling

people about what autism is and what it is not, passing on or receiving information, debunking myths and informing people about their own lives were important features of several participants' advocacy in both countries.

> *When I do advocacy, I usually start by telling people 'OK, so let's talk about what autism is'! (HU autistic self-advocate)*

Giving information may take many forms. Most common features were 'raising public awareness', 'telling people about our rights' or 'sharing personal experiences'. For autistic self-advocates, informing the public about neurodiversity was a core element of advocacy.

> *I am just trying to think what it is, what is the definition of it. [laughs nervously] I think probably it is trying to tell people that… people to see neurodiversity or autism in a more positive light and thinking of it not as deficits but difference. (UK autistic self-advocate)*

Sharing information often goes beyond 'informing the public' and may gain a specific, communal sense as well, for example when advocates or self-advocates learn from one another. Here, information is not simply about gaining knowledge or getting news about something, but rather a way of sharing ideas and getting to understand various different issues necessary to speaking up.

> Researcher*: What is self-advocacy for you?*
>
> Self-advocate: *It has taught me so many things! To understand myself and to understand others, how to behave, how to speak to others and to understand my personality and to understand others' personality as well. To understand how they speak to me and how to get to know others. (…) it is about learning, people learn about themselves. I start somewhere, then I pass on what I learned and then they [peers] pass it on to others as well. It's about spreading information. (Hungarian self-advocate with a learning disability)*

Sharing information and making it accessible to others is also central to professional advocacy, for example when advocates support families or disabled people to make decisions. Parent-advocates in both countries emphasised the need for accessible information when they support other parents. One British parent advocate saw it central to advocacy that they regularly pass on information to others about their experiences and specific problems, for example through public lectures, workshops or blog posts on the internet.

Similarly, professional advocates talked about the importance of accessible information in their work in Britain. Several participants stressed the need for accessible or adapted information, for example by providing and adapting written materials to individuals' needs, or to help them understand information by other means, for instance explaining laws, policies or other issues verbally.

> *We help with tribunals with benefits so that would be quite advocacy-like. We would give information, break information down for that person to understand their rights and different situations and we would try to help them get some form of signposting to the service that might be able to support them a little bit better. (UK professional advocate in autism)*

Sharing information is needed not only to understand laws and regulations relevant to people's lives but also to gain more confidence or knowledge to be able to speak up for themselves. In the view of several participants, sharing information is an exchange and not simply a one-way transmission of knowledge.

> *Advocacy to me is mainly centred around parents and young people understanding and knowing enough information to be able to speak for themselves and to talk to professionals and others who are involved in their lives about what's important to them and where they want to be in the future. So, advocacy is really about having enough information to be empowered to speak. (UK professional advocate in autism)*

This last statement draws attention to the third theme central to concepts of advocacy: empowerment.

Theme 3: Empowerment

A third theme, empowerment has also emerged, closely related to the previous two themes, 'speaking up' and 'sharing information'. Although this theme was present in most definitions, including ones provided by parents and professionals, it was most salient in self-advocates' accounts. In fact, for participants with a learning disability, self-advocacy is intertwined with learning, developing skills, including skills that seem crucial for someone's ability to speak up for themselves or to speak up for others, with one Hungarian self-advocate with a learning disability proclaiming *'you are learning when [you are] self-advocating. That's a life-long process'*.

However, the concept of learning for self-advocates includes not only learning but also often teaching peers, for example through training or by supporting others to build both knowledge and confidence.

> *Well, I have always thought it [self-advocacy] was speaking up for yourself and about yourself when people ask you what it is. And it's also about how you go about it, building up confidence. And then learning about listening skills, and also learning about being assertive without being aggressive. So, I always like to get them [other self-advocates] to go to training courses and things like that. (UK self-advocate with learning disability)*

Similar to sharing information and speaking up, empowerment usually gains a strong communal sense, especially for self-advocates. Supporting or '*developing*' peers were seen central to the concept of self-advocacy for participants in both countries.

> *It's just something that like… keeps you occupied. Something you can learn about. Something you can enjoy. And basically, it's just… it's a great opportunity to like… support others around you, like colleagues, to develop them… (UK self-advocate with a learning disability)*

Supporting others to be able to speak up, as seen earlier, is recognised by many advocates as a 'pinnacle of advocacy'. In this context, several advocates stated that empowerment is a 'basic level' of advocacy which should be accompanied by various ways of support.

> *I think it [advocacy] is two-fold. One is how you empower people so that they feel they have the right to have a voice. Not necessarily a voice that would be listened to, but they actually have the right to articulate what they want in their lives. So, I think that's the very basic level of advocacy. (…) The second element of advocacy is I think is how you help people to navigate the decisions that are being asked to make.* (UK advocate in learning disability)

Although empowerment was mentioned by several participants, including parents – with one Hungarian parent-advocate stating '*autistic people need support to develop competencies that are already given to non-autistics'* –, this theme seems to be more specific to self-advocates' concepts and less relevant to professionals or parent advocates. Self-advocates, especially those with a learning disability mentioned empowerment, '*gaining confidence'* and learning as central to their concept of advocacy. Empowerment for parents and professionals was more like a tool that they use to support self-advocates, and it was not present in their concept of their own skills-development as advocates.

84

The three themes presented above – 'speaking up', 'sharing information' and 'empowerment' – seem relevant to all definitions provided by participants, including definitions given by parents and professionals. These common themes constitute a certain level of consensus in how advocacy and self-advocacy are conceptualised by members of the learning disability and autism advocacy movement.

### 4.1.3 Discussion – Definitions of self-advocacy

The analysis demonstrated that definitions of advocacy and self-advocacy are far from being exact and agreed-upon by members of the learning disability and autistic advocacy movement. In fact, definitions varied and there was no consensus about them: almost all participants acknowledged that advocacy and self-advocacy are a 'broad spectrum' and can mean various things to individuals. Many participants recognised that there may only be individual definitions to advocacy and it is everyone's own decision how they conceptualise it.

This lack of consensus about what 'advocacy' means was accompanied by debates about terms. Several autistic participants, although agreed to participate in this study as 'self-advocates', repeatedly referred to themselves as 'advocates' or avoided to call themselves self-advocates for other reasons. Traditional understandings of advocacy ('a broader term including self-advocacy and also advocacy by non-disabled advocates') and self-advocacy ('advocacy is done by autistic people or people with a learning disability') were challenged by participants. Many participants held the view that both advocacy and self-advocacy can mean practices done by disabled or non-disabled people. Several terms were used by participants as synonyms to advocacy and self-advocacy, and many of these terms signalled specific types (Goodley & Ramcharan, 2010; Malinga & Gumbo, 2016) of advocacy – however, there was no consensus about what such synonyms actually mean.

On the other hand, despite the absence of a commonly agreed definition of advocacy and self-advocacy, there were also strong similarities between participants' conceptualisations. Thematic analysis identified three themes present in the definitions provided by participants. 'Speaking up', consistently with the consensus in academic literature (for example Bigby, 2015; Buchanan & Walmsley, 2006; Malinga & Gumbo, 2016) was seen central to 'advocacy' and 'self-advocacy' but also to parent advocacy and professional advocacy. Strongly related to 'speaking up', another theme 'sharing information' emerged, as both an aim of and a prerequisite to self-advocacy. A third theme, 'empowerment' was present in most participants' concepts of advocacy and self-advocacy, although this theme was more used in the context of self-development for self-advocates with a learning

85

disability – a finding also suggested in previous research (Clarke, Camilleri, & Goding, 2015; Goodley, 2005; Llewellyn & Northway, 2008). Gaining confidence, developing new skills, becoming more assertive, and learning various things were all seen as part of empowerment. At the same time, the concept of empowerment seemed less relevant to parent-advocates and professional advocates even though they sometimes mentioned the importance of skills in their own personal development. When parents or professionals employed the concept of empowerment they usually mean practices to support self-advocates or to support families or parents around them.

Despite a somehow weaker relevance of the theme 'empowerment' for parents and professionals, the relationship between these three themes, however, is not hierarchic – rather a multi-relational model that assumes that the three themes coexist and interact with the other two in people's concepts. (Figure 4.1) Therefore, the flowchart should be seen as a dynamic model where each theme gains emphasis or importance appropriate to individuals' own needs, preferences, and a number of other factors relevant in individual circumstances.
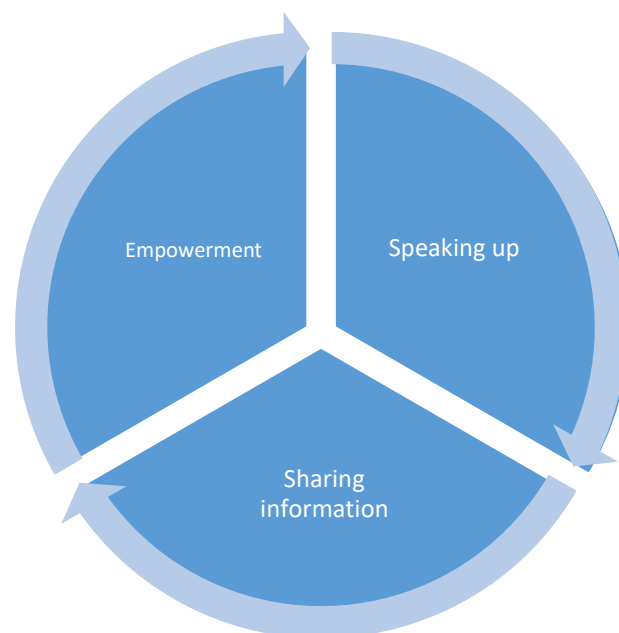
Figure 4.1 Relationship between themes of concepts of advocacy and self-advocacy

Each theme has a strong reliance on the other two. Sharing information may be a way of empowering others; speaking up is possible because one feels empowered; empowerment may be possible if information is given and received by advocates and self-advocates. All three themes have been framed by several participants with a strong sense of community through which advocacy and self-advocacy are practised – sharing information, 86

empowerment and speaking up are achieved with and through the help of others, such as peers, supporters or professionals.

<center>***</center>

In this section, the attention was given to different definitions of advocacy with the aim to identify common concepts of advocacy and self-advocacy in participants' accounts. Results of this analysis are limited: although there were common themes that were present in both advocates' and self-advocates' definitions, no consensus definition can be established. Erratic and sometimes controversial terminology and the subjectivity of definitions establish serious limitations to giving a consensual concept of advocacy and self-advocacy.

To fill in this void and in order to further conceptualise advocacy and self-advocacy, an additional analysis will be carried out in the following section, by offering a new, practice-based approach to self-advocacy.

4.2 SECOND ANALYSIS: SELF-ADVOCACY BEYOND STRUCTURES AND ACTORS

Based on the literature review in Chapter 2 and on participants' definitions in the previous section, various different forms of self-advocacy and advocacy have been briefly introduced and discussed. Such forms included individual advocacy or individual self-advocacy, self-advocacy groups, parents' advocacy groups, and other organisational forms of advocacy such as charities or DPOs. All these forms of advocacy are in fact descriptive categories that maintain a dominantly *structural* view on the disability advocacy movement, with a strong emphasis on social structures such as organisations, or rules that may influence what organisational form people choose to do advocacy in. This emphasis on social structures when explaining social phenomena is commonly associated with *structuralism or functionalism* in social theory (Giddens, 1989).

Self-advocacy or other types of advocacy can also be looked at from another viewpoint, from the perspective of individuals navigating between forms of advocacy. This perspective has briefly been touched on in the previous section, for example when advocates disputed whether a consensual concept of advocacy exists at all, or when they used terms in highly idiosyncratic meanings.[18] In this aspect, the emphasis is always on the *actor* or *individual* who advocates, and how their individual backgrounds, properties (such as being a parent versus being a disabled person) or how their decisions impact the form of advocacy they choose. This strong emphasis on individuals, their choices, actions and their agency is close

---

[18] A further analysis will consider this individual perspective in Chapter 5 which will present different personal pathways to various forms of advocacy.

to what social theorists often call – following Max Weber's original German term *methodische Individualismus* (Weber, 1978) – *methodological individualism* (Heath, 2015).

These two approaches represent two distinctively different social theory traditions. There have been longstanding debates among social theorists whether *social structures* on the one hand or *individual agency* on the other have primacy in influencing or defining human behaviour (Giddens, 1979). However, emphasis can also be given to one core element of advocacy: practice, or in other words, *what advocates do* when they advocate.

During interviews and focus groups, participants mentioned various activities they carry out when they advocate or self-advocate. In order to further conceptualise advocacy and self-advocacy, in the following analysis, the focus will be on these activities, actions or practices. (*Activities*, *actions* and *practices* will be used as synonyms across this chapter, however, a distinctive definition will be given to *practice*, based on practice theorists' works.) Instead of trying to untangle the myriad of idiosyncratic meanings people attribute to certain terms, the following analysis will look at what people do when they (self-)advocate. It is hoped that the following analysis will be able to avoid the methodological barriers imposed by language in the previous analysis

To reconceptualise advocacy and self-advocacy, a third tradition in social theory, '*practice theory*' (Schatzki, 1996) will be introduced and used for data analysis. Practice theory includes a wide array of different concepts in social theory and social research, and empirical or theoretical inquiries can use many different approaches while still adapting practice theory (Reckwitz, 2002). Before posing practice theory-inspired questions about learning disability and autism advocacy, it is useful to look at what 'practice theory' means in contemporary social theory, and how it is used for analysing empirical data.

4.2.1 Introducing practice theory

Practice theory has a long tradition in social theory and social research. Elements of practice theory are already found in works of French theorist Pierre Bourdieu who put forward 'praxeology' as a term in his work Outline of a Theory of Practice (1972). Bourdieu, together with English sociologist Anthony Giddens put an emphasis on practice, that is just as important to them when understanding the social world as are structure and agency. Anthony Giddens (1984) famously stated that '*principles of order could both produce and be reproduced at the level of practice itself*' (Giddens, 1984 p. 376). Other philosophers also developed or used elements of practice theory in their works, for example, Ludwig Wittgenstein described language as '*a set of practices embedded in convention*' (Couldry,

2012) or Michel Foucault, who was concerned with practices such as punishment or incarceration in the West (Foucault, 1977). Feminist philosopher Judith Butler is also recognised to have built on practice theory in her works about performative gender studies (Butler, 2011).

Based on such earlier works, others such as Stephen Turner (1994) further developed practice theory, elaborating the notion of both 'tradition' and 'tacit knowledge' but also pointing out the fuzziness of the concept of practices. From the recent wave of practice theorists, Theodor Schatzki has grown influential in theorising the notion of practice (Schatzki, 1996). For Schatzki, practice became a central and highly complex theoretical concept that is more than just a descriptive category of the social world. He implied that seemingly mundane practices such as doing leisure activities have particular organising properties in the social world. In fact, Schatzki stated (2001, p.3) that the social world is constituted by practices, and '*the social is a field of embodied, materially interwoven practices centrally organised around shared understandings*'.

Practice theorists see the concept of practices central to understanding individuals, systems, structures, institutions, or even language – and how these interact with each other. Practice theory is more interested in the 'everyday' or 'life worlds' (Reckwitz, 2002) than in 'structure'. Reckwitz, who has tried to synthesise the work of other theorists including Bourdieu, Schatzki and Foucault, provided a rather concise – or as he called it '*idealised*' – concept of practice that is a

> '*routinized type of behaviour which consists of several elements, interconnected to one another: forms of bodily activities, forms of mental activities, 'things' and their use, a background knowledge in the form of understanding, know-how, states of emotion and motivational knowledge.*' (Reckwitz, 2002, p. 249)

Practice theory has positioned itself between other traditions in social theory such as structuralism or methodological individualism. As opposed to these two dominant traditions in social theory, practice theorists offer a conceptual alternative. For example, for Reckwitz (2002), practice theory constitutes distinctively different ways of thinking about concepts familiar to social theorists. The below list of elaborations about such concepts of social theory, based on Reckwitz (2002, p. 252-257), attempts to aid our understanding of practice theory in the context of studying disability advocacy.

- Body is '*a practice [that] can be understood as the regular, skilful "performance" of (human) bodies*'.

- Mind is '*a social practice [that] consists of certain bodily and certain mental activities'*.

- Things are not only objects but also '*routinised relations between several agents (body/minds)'*.

- Knowledge is '*a constitutive element of practice*' and '*not only a way of understanding*' but '*also a know-how knowledge'*. Therefore '*wants and emotions (…) do not belong to individuals but – in the form of knowledge – to practices'*.

- Language or discourse are '*practices [that] are one type of practices among others*' and '*language exists only in its (routinised) use*'.

- Structure or Process are important in the concept of routines and '*the nature of social structure consists in routinisation'*.

- The Agent / Individuals are the '*body/minds who carry and carry out practices*' so '*the social world is first and foremost populated by diverse social practices which are carried out by agents*' who '*"consist in" the performance of practices'*.

Despite efforts by practice theorists like Schatzki, Reckwitz or Turner, practice theory has not one single agreed-upon coherent concept, in fact, it is not even a unified theory. As observed by others, practice theory remains a '*body of highly diverse writings by thinkers who adopt a loosely defined "practice approach"*' (Postill, 2011). However, this diversity within practice-based theories and approaches has become a fertile ground for innovative research in other disciplines such as consumerism studies, cultural studies, anthropology and importantly, in contemporary media studies where theorists and empirical researchers were similarly inspired by a renewed focus on practices. In the following section, applied social research will be discussed that used practice theory in highly innovative ways.

Practice theory in social research

Practice-based approaches have been used in social research in various contexts, both when developing new theory and in analysing empirical data. For example, Alan Warde (2005) made a convincing point when he argued for the need for renewed inquiries into the relationship between everyday practices and consumption. Consumption, he asserted, is more than just the simple purchasing of objects or commodities, or a market exchange. Warde pointed out that '*consumption is not itself a practice but is rather a moment in every practice'* (Warde, 2005, p. 137) and he illustrated this point by looking at motoring practices in Britain. For Warde, consumption is not an action that is made primarily because individuals want to purchase, own or use something but consumption '*occurs within and for the sake of practices'* (Warde, 2005, p. 145). He also argued that practice-based inquiries

may allow us to ask new questions that illuminate aspects of consumption not discussed before. For example, different practices may offer different internal or external rewards available to people holding different positions within certain practices. He stated that '*contrasting understandings, levels of practical competence, and degrees of involvement generate behavioural variation*' (Warde, 2005, p. 147) – an observation that may be particularly useful for this study in understanding whether factors such as '*practical competence*' or '*degrees of involvement*' influence the practices disability advocates or self-advocates do. Warde's inquiry showed that practice theory may be able to inform new questions, for example: what types of practices are dominant and what type of practices are secondary; what is the range of practices individuals engage with; or what are the typical combinations of certain practices (Warde, 2005, p. 149).

In another discipline, media studies, a 'practice turn' was demonstrated in the works of several researchers of the field (Bräuchler & Postill, 2010; Couldry, 2012). Leading theorist Nick Couldry called (2012) for a renewed, practice-based approach to understanding contemporary media, mostly because of the complexity and speed of current tendencies in both media usage and media production. Couldry stated that only by looking at practices can we understand certain phenomena in media. Importantly, Couldry demonstrated that a new, practice-based analysis may reveal unexpected trends in social behaviour. For example, Twitter was assumed by government and media to be used for incitement during the 2011 summer riots in Britain – however, a later survey indicated that the most prevalent use of Twitter during this period was, in fact, reacting to the riots (Couldry, 2012, p. 42).

Other media theorists have further opened the field for practice theory-inspired inquiries in media studies (Bräuchler & Postill, 2010). Postill and his co-authors demonstrated that many different fields within media studies can potentially benefit from practice-based approaches, including inquiries such as the anthropological study of media audiences in the United States; ethnographic research of news media production in North India; or the daily use of ICTs (Information and Communication Technologies) in Danish families' everyday lives. Notably, Postill and his colleagues also identified strong limitations of practice theory in applied media studies, for example, practice-based approaches cannot contribute to the understanding of one-time events or 'world-historical moments', and how they occur, because these events seem to possess little of the regularities practice theory is able to engage with.

Practice theory, despite its impact in other fields of social sciences, has been rather absent in disability research. One exception is that of Mladenov's inquiry into the relationship

91

between disability and critical theory (Mladenov, 2016). Mladenov was inspired by practice theory in his study on disability assessments in Bulgaria and showed convincingly that certain practices contribute to *dis/ablism*, a term developed to mark '*behaviours that render some people inferior based on their impairments*' (Mladenov, 2016 p. 3). Mladenov's concept of practice follows that of Schatzki's – practices are '*patterned networks of interrelated activities mediated by humans and non-human entities*' (Mladenov, 2016 p. 3).

Another practice theory-inspired approach was offered in the context of learning by support staff. The analysis employed the concept of 'Communities of Practice' which is defined as a '*group of people who share a concern or passion for something they do and learn how to do it better as they interact regularly*' (Wenger-Trayner & Wenger-Trayner, 2011). The concept of Community of Practice was successfully applied to analyse practice-based learning in the staff of disability services in Britain (Bradshaw & Goldbart, 2013). It was found that staff of services function as 'Communities of Practice' where experiential knowledge, for example learning through practice was very important. The Community of Practice approach was also employed by Lawthom (2012) who appraised British DPOs' advocacy and found that DPOs may indeed function as Communities of Practice that offer new ways of learning for disabled people.

Practice theory and disability advocacy

Studies on disability advocacy and self-advocacy have long given consideration to activities, or '*self-advocacy in action*' (Goodley, 2000), however, practice-based approaches into self-advocacy remain largely absent.

As presented in Chapter 2, although previous studies have usually included – often rich – data on what advocates and self-advocates do, however, most studies have employed a specific thematic focus for which activities are demonstrative elements and less often analytical categories. For example, studies focused on the internal working of self-advocacy collectives and looked at activities to assert the structure (e.g. the organisation) itself (for instance Chapman, 2005; Llewellyn & Northway, 2008; Tilley, 2006a; Tilley, 2006b; Whittell et al., 1998). Other studies also focused primarily on structural issues – such as power struggles between different types of organisations –, or achievements of movements, and gave mentions to the actual advocacy or self-advocacy actions or practices primarily in the context of these issues (Balázs & Petri, 2010; Bertilsdotter et al., 2015; Callus, 2014; Chamak, 2008; Waltz et al., 2015). Historical overviews of advocacy and self-advocacy also tend to see activities and actions as representations of certain historical periods or typical organisational forms (Buchanan & Walmsley, 2006; Bylov, 2006; Ledger & Tilley, 2006; Waltz, 2013). Even

studies that employed an impressively comprehensive approach, looking at both internal and external organisational matters, individual life stories and historical contexts, saw practices mostly as demonstrative elements (Goodley, 2000) instead of putting them in the centre of their analysis. Indeed, despite various studies that looked at advocacy activities, practices have remained descriptive and not analytical categories, mostly to serve structure-centred or agent-centred inquiries.

This is not to say that previous studies have not been considering the importance of self-advocates' actions. Practices have been treated in disability activism research almost as 'padding' in a complex system of organisations and individuals: they have been analysed in order to appraise agency or to assess structures and how these two interact. This approach, of course, is far from inadequate. In fact, disability studies has long been concerned with personal independence (Barnes, 2012), or the autonomy of the individual – therefore the emphasis on individual agency and seeing activities as demonstrations of empowerment is often characteristic of studies on self-advocacy. From the viewpoint of disabled people's agency, practice theory may even look controversial with its prominence of – often unconsciously or tacitly done – practices over individuals or structures.

In what follows, a practice-based analysis will be proposed to appraise self-advocacy. This turn to practices serves important purposes.

First, after assessing concepts of advocacy in earlier sections of this chapter, it remains mostly unanswered what different members of the learning disability and autism advocacy movement actually do when they advocate.

Second, there may be a concept of advocacy or self-advocacy that remains implicit or tacit for advocates or self-advocates. Participants noted that '*advocacy can mean so many things*' and that '*people aren't necessarily aware when they are being advocates*'. One participant even stated '*I don't have the reflective knowledge to say that this is me doing advocacy*' while another person likened being an autistic self-advocate to performing '*in my all life*'. These observations call attention to the nature of knowledge in the concept of advocacy. There may be knowledge participants are not aware to be having even though they are practising activities that represent that knowledge. Practice theory offers a useful analytical tool to reveal 'implicit knowledge' because *knowledge* in practice theory has a distinct definition. 'Tacit knowledge' has been conceptualised by practice theorists in this context, although the concept still remains somewhat elusive (Collins, 2001). For Reckwitz, knowledge comprises of both understanding, know-how, and even 'wanting and feeling', thereby implying that

actors may not always be aware of the knowledge they are carrying when doing practices and extending the realm of knowledge beyond cognitive processes (Reckwitz, 2002). It is possible that knowledge required to do advocacy is largely acquired by members of the disability movement through peers or the community they are part of, making the concept of Community of Practice (Wenger, McDermott, & Snyder, 2002; Wenger-Trayner & Wenger-Trayner, 2011) highly relevant in the context of advocacy.

In order to reveal multiple layers of what self-advocacy means, it is necessary to change the view on advocacy and see it as something that is carried out through – using Mladenov's (2016) concept – *'patterned networks of interrelated activities'* or simply put: through everyday practices.

4.2.2 A practice-based analysis of self-advocacy

The following analysis will build on a practice-based approach to conceptualise self-advocacy and advocacy. As presented earlier, and also observed by several authors (Postill, 2011; Reckwitz, 2002; Turner, 1994), practice theory includes various different, loosely defined practice-focused approaches which can be used for empirical research in diverse ways (Bräuchler & Postill, 2010). This analysis will not follow one strictly defined practice theory but takes inspiration from practice theorists works, building mostly on notions established by German theorist Andreas Reckwitz (2002).

4.2.2.1 Methods

Practices of advocacy and self-advocacy will be looked at based on mentions of activities and practices ('what advocates do') during interviews and focus groups. In order to conceptualise advocacy and self-advocacy, two questions are proposed in this analysis:

1. Is there a difference between the practices self-advocates do and practices other advocates do as part of their everyday advocacy?
2. What are the emerging themes among practices that members of the learning disability and autism advocacy movement do?

Various research methods have been employed in practice-based studies. Although participant observation or other types of ethnographic data collection are popular in practice-based empirical studies (Bräuchler & Postill, 2010), the flexibility of practice theory allows for diverse methodologies, including the analysis of texts such as interview transcripts. For example, thematic analysis of semi-structured interviews was used in a

practice theory-inspired study to evaluate the online internet activity at a network of Mexican universities (Gonzalez & Cox, 2013).

To answer the two questions, practices mentioned by participants will be looked at by using content analysis (Hsieh & Shannon, 2005). Conventional content analysis is a popular method to analyse textual data – such as interview transcripts – and to describe a phenomenon with limited existing theory (Hsieh & Shannon, 2005 p. 1279). Content analysis is also used to describe hierarchical or other types of relationship between different themes in a set of data.

For the analysis, the researcher read all transcripts several times, scanning the texts for mentions of practices. Mentions of activities or 'things' people do as part of their advocacy were identified and organised into a list or catalogue of practices (see Appendix 24). The list includes activities mentioned by participants as something they themselves do, but in some cases also activities participants referred to as things that other advocates do, often speaking in terms of 'we', for example in the context of an association or community. Similarly to earlier chapters, the analysis employs a broad approach and includes practices mentioned by both self-advocates and other advocates, such as parents or professionals. This broad view ensures that any kind of activity that participants see as part of learning disability or autism advocacy gets recorded. This approach also allows comparing what self-advocates and what other advocates do. Importantly, interviews and focus groups consist of the interpretation of (i.e. speaking about) practices by those who do those practices, therefore giving voice to insightful and experiential knowledge about what advocates and self-advocates do. By analysing interviews and focus group transcriptions, this experiential knowledge of everyday practices is getting a review.

There is a further reason why a practice-based analysis is meaningful in this study: data itself informed the decision to develop a practice-based inquiry. Interviews and focus groups consisted of a myriad of activities participants talked about. They used practices to explain their concepts of advocacy and self-advocacy. Repeated readings of transcripts revealed that talking about practices is absolutely central for participants in their making sense of advocacy and self-advocacy.

Transcripts contained robust data: 43 participants mentioned practices in over 50 hours of recorded material over 300 times. This provided a large set of data about what people do as part of their everyday (self-)advocacy. In fact, transcripts were so rich in data that the scanning and listing-up of mentions of practices reached saturation after analysing three

focus groups (n=11) and six interviews. Interviews and focus groups were sampled to give a balanced representation of all participant groups: parent-advocates; professional advocates; and autistic self-advocates and self-advocates with a learning disability. One focus group and one interview with members of each of these groups were selected, and in the case of professional advocates – in the absence of a focus group interviewing only professionals –, three interviews were sampled. This sampling method ensured that each of the four participant groups has around three to three and a half hours of recorded material representing their views in this analysis.

There were two selection criteria for choosing practices from transcripts. First, every practice mentioned by participants was selected for this analysis, even if the given practice had already been mentioned before by other participants. This decision was taken to ensure that the list of practices gives an opportunity to identify patterns in what different advocates and self-advocates do – not only the identification of practices is important but also to see how dominant some practices are among other practices. Accordingly, if some practices were mentioned by many participants then this practice appears several times in the list and other practices that got mentioned by fewer participants are featured fewer times. However, if one single participant mentioned the same practice several times throughout an interview – for example during a monologue about a topic, or as part of a dialogue about a specific issue in a focus group -, then only one mention is used for this analysis. This decision was taken because of the limitations of the methodology employed: the semi-structured interviews and focus groups were not designed originally to collect information on practices of advocacy (Chapter 3) and they covered a lot of other issues, which consequently meant that some practices may have been emphasised and mentioned several times by participants because, for example, they were telling a story related to a given practice.

Another selection criterion was also applied: activities that participants mentioned explicitly as one-time actions were not included if it was clear from the transcription that participants talked about an irregular activity. For example, a self-advocate mentioned an incident – an open conflict between audience and a presenter – that happened at a conference; this conflict was presented as an exceptional one, therefore, it did not get recorded in the list of practices. This decision was taken because practice theory is concerned with routines or regular activities (Schatzki, 2001) and not ad hoc or accidental actions.

Mentions of practices were copied verbatim from transcriptions into a list in MS Word, only slightly amending or altering the wording, to allow for a contextual understanding of the practice without the surrounding text. The practices are therefore displayed by focusing on

96

the action (verb/gerund) with giving only the necessary clauses to illuminate the particular meaning of the verb.

4.2.2.2 Results – an analysis of practices in advocacy and self-advocacy

First, the full list of practices (see Appendix 24.) was looked at to identify general patterns or themes and to familiarise the researcher with the practices. The list demonstrated the extremely wide range of different practices learning disability or autism advocacy may include. In the first and second part this analysis, practices will be categorised in different ways to highlight differences between both different types of practices, and also differences between participant groups. Then, in the third part of the analysis emerging themes within practices will be appraised.

Results - an analysis of practices in advocacy and self-advocacy

In the first part of this analysis, practices were categorised per participant groups to highlight differences between what advocates and self-advocates do. The grouping of practices into participant categories allowed for clear comparison from a practice-based point of view, by identifying practices that were done dominantly by one group of advocates but not by others. For example, if some practices were done dominantly by professional or parent-advocates but not by self-advocates, then it may explain why non-disabled advocates usually hold more dominant positions in the movement while self-advocates remain often invisible.

Then, in the second part emerging themes within practices were identified. For the identification of these themes, thematic analysis was used. The list of practices was read several times by the researcher to identify common themes. The grouping of practices into themes was done manually, in MS Word. The analysis will be done to appraise whether there is further difference between practices mentioned by advocates such as professional or parent-advocates vis-à-vis self-advocates. The presentation of data will be based on differences between four groups: parents, professionals and self-advocates (autistic self-advocates separately from self-advocates with a learning disability). This separation of parents, professionals and self-advocates follows a traditional view that these groups have been often separated by tensions and debates about various issues, including the aims and content of advocacy (Bylov, 2006; Waltz, 2013; Wehmeyer et al., 2000).

Who does what?

Practices were grouped into four categories, from the point of view of actors, along the previously stated question: is there a difference between the practices self-advocates do and practices other advocates do as part of their everyday advocacy? (see Table 4.2)

Participants	Practices of advocacy	
People with a learning disability	Learning to introduce ourselves in hospitals, offices, schools, at a party or elsewhere Getting to know ourselves and others or our environment Learning how to handle money [practising the] Nothing about us without us [principle] Standing up for our rights every day Gaining confidence and be visible in the world Exchanging information/experience with peers Helping each other Going to conferences and meeting others Preparing for conferences Telling politicians what we want To protect your peers Writing letters	Passing on information Giving voice to peers Getting help to protect ourselves Putting things on a website, editing a website Writing things up Giving training Learning things Speaking with others (including peers) Developing new skills To become independent To be able to protect yourself To read things on the internet Writing up articles Learning how to handle conflicts
Autistic people	Fighting for benefits Telling people what autism is (what it is not) Passing on information to non-autistic people Issuing statements (in the policy context) Giving interviews in media (press, tv) Doing research on therapies, evidence-based interventions Defending rights, using the law Making videos, putting them online Working together as a community (with autistic people) Supporting each other, even just solidarity Educating neurotypical people about autism Starting or signing petitions	Administration in organisations Myth-busting about autism Reading on autism and other stuff Helping autistic peers Developing websites Making films, videos Developing new skills, learning Doing graphic design Raising public awareness, e.g. by giving lectures Sharing experiences with peers Blogging, vlogging Being active on social media Networking, meeting others
Parent-advocates	Writing letters to authorities Reading the law Protecting rights Speaking for other families Organising meetings (including for other parents) Bringing together parents Making sure my kid is OK in the class Representing the interest of their children (incl. other families) Representing the interest of the whole family Writing a blog Writing books, articles Being on social media, Twitter, or Facebook Getting in touch with other parents on social media	Establishing an organisation Speaking in the media Going to conferences Speaking at conferences Trying to change the law, lobbying Developing skills (law, financial, leadership, negotiation skills etc) Supporting self-advocates Teaching advocacy skills Supporting 'our' children (incl. in other families) Influencing policies or laws Giving training to professionals Travelling a lot (e.g. to conferences) Not accepting refusal by authorities
Professional advocates	Learning about human rights & the movement Organising rallies Making and using leaflets, fliers etc Pushing for legal changes, lobbying Participating in drafting laws and policies Organising conferences and meetings Going to authorities, social and health services Going to ministries and city councils To train and support self-advocates Making Internet accessible for SAs with LD Writing to politicians Going to training or workshops to gain skills Paperwork, administration of cases Participating in formal government consultations Competing with other advocacy organisations	Teaching about various issues Telling people about their rights Litigating cases Doing NHS complaints or helping people putting together care plans Making sure information is accessible to people Structuring information Going to tribunals Visiting families Supporting clients emotionally Talking things through with clients Managing an organisation Entering confrontations or conflicts Running legal aid services Talking to media

Table 4.2 Examples of practices per participant group

The list of practices in Table 4.2 demonstrates that advocates and self-advocates engage with a very broad variety of practices as part of their everyday activities. Importantly, only slight differences appear between what different participant groups do as part of their advocacy – nearly all practices seem to be common for both advocates and self-advocates. Few differences seem to be present, for example the gaining of basic skills for some self-advocates with a learning disability ('*learning to introduce ourselves in hospitals*'; '*learning how to handle money*', '*becoming independent*' etc.) is specific to their group; or professionalised practices of advocacy ('*going to tribunals*', '*doing NHS complaints*') are probably more specific to those working as 'professional advocates' in the United Kingdom. Some practices like '*myth-busting about autism*' or '*supporting their children*' may first seem specific to a certain group – autistic self-advocates and parents, respectively. However, both of these practices could also be belonging to other groups: myth-busting about autism is often done not only by self-advocates but by parents or professionals as well; and similarly, supporting children may be a practice not only for parent-advocates but also for professional advocates or even self-advocates who have children.

From this point of view, very few practices in Table 4.2 can be associated with exclusively one certain group of advocates: for example, '*learning about rights*', '*attending conferences*', '*pushing for legal changes*', '*writing letters*', '*going to authorities*', '*giving trainings/lectures*' or '*supporting each other*' were mentioned by both parents, professionals and self-advocates as part of their everyday activities. This finding suggests that many advocacy practices, although they may require skills or resources, could be done by any of the historically separated groups of advocates such as parents, professionals or self-advocates.

Common themes of practices

The broad diversity of practices does not mean there is a lack of common themes in what advocates and self-advocates do. In fact, there are several practices that connect groups of advocates and self-advocates. Five types of core practices or themes seem to be integral to advocacy across different groups of advocates.

1. One seminal theme across participant groups is '*informing and being informed*'. Numerous practices were mentioned in this context, on the one hand as learning or developing one's skills, and on the other hand as teaching and giving information to others / to the public in different ways.

- Learning is a common practice in advocacy. Information gained or learned enables people to do advocacy. Practices mentioned include, '*learning*', '*learning about human*

rights and the movement', *'reading on autism and other stuff'*, *'learning how to handle conflicts'*, *'developing new skills'*, *'going to workshops to gain skills'*, *'reading the law'* or just *'reading things on the internet'*. These are all practices that most advocates and self-advocates regularly do as part of their advocacy work and not only as prerequisites to advocacy: several participants mentioned these activities as 'ongoing'. Learning is something that most participants regularly do even after years of experience in disability advocacy.

- Passing on information is also a salient practice for nearly all advocates and self-advocates. This can take many forms and includes teaching, giving speeches or handing out written materials. Information is regularly and systematically passed on to others and target groups include peers, people in the community or the wider public. Practices mentioned by participants include *'exchanging information or experience with peers'*, *'training self-advocates'*, *'giving training'*, *'telling people what autism is and what it is not'*, *'speaking at conferences'*, *'telling people about their rights'*, *'raising public awareness'*, *'myth-busting about autism'*, *'teaching about various issues'*, *'educating neurotypical people about autism'*, and *'teaching advocacy skills'* to peers.

- One type of practice was often phrased by participants in a specific way that implied the development of basic skills, for example '*learning how to introduce ourselves in hospitals, offices, at a party or elsewhere'*, '*becoming independent'*, '*learning how to handle money'*, or '*getting to know ourselves'* – these may be seen irrelevant for some advocates, whilst they mean a type of learning that is a core practice for other self-advocates. These practices expose a 'skill gap' within the movement: some advocates are more skilled than others and training and support needs may differ largely between advocates.

2. Another core theme is '*using media'* that is closely related to the previous theme, getting or giving information. Media is seen as a tool to transmit or receive information necessary for advocacy and nearly all participants mentioned using the media as integral to their advocacy. This theme signals that popular means of communication, such as the internet, mobile applications or social media are key tools for advocates and self-advocates. 'Using media' includes both consuming and producing media content – in fact, much of the mentioned practices are about producing media content.

- Online media-related practices include *'developing websites'*, *'blogging or vlogging'*, *'getting in touch with other parents on social media'*, *'putting things on a website, editing*

a website', *'reading things on the internet'*, *'making videos, putting them online'*, *'writing a blog'*, *'signing [online] petitions'* or simply just *'being on social media, Twitter or Facebook'*. This shows that seemingly mundane practices such as being on Facebook or 'reading things on the internet' can, in fact, be part of one's advocacy.

- Offline, more traditional types of media contents were also produced by participants. These include *'making films'* – which can be shown at a training or conferences, or may be put online – , *writing up articles'* or *'writing articles or books'*, or *'making and using leaflets and fliers'*.

- Importantly, the production of media content includes specialised or adapted information. In learning disability or autism advocacy the design of media content should be accessible to as many people as possible, including those with an intellectual disability or other types of learning difficulties. Several such practices were mentioned, including *'making the internet accessible for self-advocates with a learning disability'*, *'structuring information'* or *'making information accessible to everyone'*. Notably, these practices were mentioned in relation to all audiences that may need adapted or accessible content, including parents of disabled children.

3. A third theme is closely related to solidarity, reiterating Reckwitz's definition on practices that includes 'states of emotions' (2002) – this theme can be labelled as *'supporting each other'* or *'being in the community'*. Practices articulating forms of solidarity are present in various contexts.

- Solidarity is often practised through giving or accepting help. Help was mentioned as *'helping each other'*, *'helping autistic peers'*, *'supporting clients emotionally'*, *'supporting our children'*, *'supporting self-advocates'*, *'protecting your peers'*, *'getting help to protect ourselves'*, or *'supporting each other, even just solidarity'*.

- Supporting others or belonging to a community were frequently framed as correspondence or just *'being in touch'* with others, for example *'networking, meeting others'*, *'speaking with others'*, *'getting in touch with other parents on social media'*, *'bringing together parents'* or *'going to conferences and meeting others'*. Being in touch with peers is a practice that enables people to exchange information, but also to give or to get support, 'even just solidarity'. This theme indicates that communication with peers in any possible ways – online or offline – is a practice integral to advocacy, and it has important emotional properties for parent-advocates and self-advocates as well.

- This theme showed less salience for professional advocates, however, they also mentioned practices outside their strictly understood job descriptions, for example 'visiting families' or 'giving emotional support' to their clients.

4. Not surprisingly, one of the most salient themes among practices was *'speaking up'*, phrased in various different ways. 'Speaking up' is widely used as a blanket term to describe the main, essential element of all disability advocacy practices (Buchanan & Walmsley, 2006; Chapman et al., 2012; Goodley & Ramcharan, 2010; Malinga & Gumbo, 2016; Shore, 2004; Walmsley, 2002), however in this analysis it is only one among several types of practices that advocates do as part of their advocacy.

- Practices under 'speaking up' were sometimes mentioned as general statements such as *'standing up for our rights'*, *'protecting rights'*, *'representing the interest of the whole family'*, *'doing nothing about us without us'*, *'not accepting refusal by authorities'*, *'entering confrontations or conflicts'*, *'going to authorities'* or *'influencing policies or laws'*.

- Often, 'speaking up' is framed as an actual advocacy action, for example *'telling politicians what we want'*, *'organising rallies'*, *'doing street actions'*, *'organising conferences'*, *'going to ministries or city councils'*, *'litigating cases'*, *'going to tribunals'*, *'participating in formal government consultations'* or – for some professional advocates in Britain – *'doing NHS complaints'*.

5. Finally, certain practices relate to generic *organisational/bureaucratic duties*, present in all 21st-century organisations regardless of their nature. These practices are assumed to be more relevant in formalised advocacy and self-advocacy than in individual advocacy or in informal group advocacy. Practices under this theme include *'managing an organisation'*, *'competing with other advocacy organisations'*, *'paperwork and administration of cases'*, *'paperwork at organisations'*, and *'establishing an organisation'*. This theme was less salient for autistic self-advocates where only one practice 'administration in organisations' was mentioned. This difference can be explained by the fact that almost all autistic participants worked outside formalised organisations. Self-advocates with a learning disability did not mention organisational duties at all, which suggests that those involved in self-advocacy groups may not be involved the administrative duties.

The above list of thematic groups of practices demonstrates that (self-)advocacy is much more than just 'speaking up'. Many practices, including those under 'using the media', 'supporting others', 'organisational duties' and the sub-theme 'learning' go beyond simply

'speaking up' and they are not at all specific to disability advocacy but may be present in many other occupations in the 21st century. These are activities that draw attention to important, and less-recognised activities in advocacy and self-advocacy. In fact, they propose an alternative, practice-based definition of advocacy: *advocacy and self-advocacy are a collection of complex, routinely executed actions embedded in everyday practices, that may or may not result in speaking up*.

In fact, a substantial part of everyday activities in advocacy are actually rather generic everyday activities that many people do routinely. Such everyday practices may not be separated from other practices people do, because advocacy and self-advocacy are often woven into other practices. People write, send and read emails; they do 'paperwork' or other bureaucratic duties; they spend time on social media to correspond with others; they attend training courses, workshops or conferences; they meet others; they travel to meetings or other events; they read things such as laws, articles or other materials; they organise meetings; they support others, for example, they talk things through with them or they just simply give signs of solidarity. The list could be continued almost infinitely depending on advocates' personal lives and chosen activities. Importantly, people do all these practices in various possible combinations, appropriate to their lives, preferences, choices, skills or resources available to them. Indeed, advocacy and self-advocacy are much more than just practising 'speaking up'. These other, '*para-advocacy*' activities include routinely done practices that may take up a significant amount of time and resources advocates and self-advocates.

Furthermore, these activities are not seen as merely auxiliary to 'speaking up'. Participants' statements indicate the contrary: 'para-advocacy' practices are in fact necessary to 'speaking up' or integral parts of being an advocate. For example, in order to go to a conference to 'speak up', one advocate needs to prepare for the travel, correspond not only with organisers but peers who may be attendees, plan interventions, discuss various details etc. All these practices are done routinely, and often beyond strictly understood advocacy activities. Using Reckwitz's statement about agents who '*consist in*' routinized practices (Reckwitz, 2002, p 257), it is the assertion of this analysis that self-advocates and advocates may also 'consist in' practices they do, and the line between advocacy and other practices is often blurred in their lives.

4.3   DISCUSSION: A COMMUNITY PERTAINING DISPARITIES

The analysis found an overlap between practices of different groups of advocates and self-advocates. (see Table 4.3)

	Professional advocates	Parent advocates	Autistic self-advocates	Self-advocates with a learning disability
Informing and being informed	Learning about human rights & the movement Going to training/workshops Teaching about various issues Telling people about their rights Running legal aid services	Reading the law Developing skills (law, financial, leadership, negotiation skills etc) Teaching advocacy skills Giving training to professionals Being on social media, Twitter, or Facebook	Telling people what autism is (and what it is not) Passing on information to non-autistic people Myth-busting about autism Reading on autism and other stuff Developing new skills, learning	Passing on information Learning to introduce ourselves Getting to know ourselves and others, or our environment Learning how to handle money Giving training Learning things
Using media	Making and using leaflets, fliers etc Making Internet accessible for SAs with LD Making sure information is accessible to people Talking to media	Writing a blog Writing books, articles Being on social media / Twitter / Facebook Getting in touch with other parents on social media Speaking in the media	Giving interviews in media Making videos, putting them online Developing websites Blogging, vlogging Being active on social media Doing graphic design	Putting things on a website, editing a website To read things on the internet Writing up articles
Supporting each other / Being in the community	Visiting families (of autistic children) Giving emotional support to clients	Speaking for other families Going to conferences Bringing together parents Supporting self-advocates Supporting 'our' children (incl. in other families)	Working together as a community (with autistic people) Supporting each other, even just solidarity Helping autistic peers Sharing experiences with peers	Helping each other Giving voice to peers Getting help to protect ourselves Speaking with others (incl. peers) Going to conferences and meeting others
Speaking up	Organising rallies Pushing for legal changes, lobbying Participating in drafting laws & policies Going to ministries and city councils Litigating cases Going to tribunals	Writing letters to authorities Protecting rights Representing the interest of the whole family Trying to change the law, lobbying Not accepting refusal by authorities Influencing policies and laws	Fighting for benefits Issuing statements (in the policy context) Defending rights, using the law Starting or signing petitions	[practising the] Nothing about us without us [principle] Standing up for our rights every day Gaining confidence and be visible in the world Telling politicians what we want
Organisational/bureaucratic duties	Paperwork, administration of cases Participating in government consultations Managing an organisation	Organising meetings Establishing an organisation Travelling a lot (e.g. to conferences)	Administration in organisations	-

Table 4.3 Examples for overlapping themes per participant group

This finding suggests that the learning disability and autism movement may be similar to a 'Community of Practice' or it may be composed of several 'Communities of Practices' (Wenger-Trayner & Wenger-Trayner, 2011). Community of Practice is a known phenomenon in educational theory which emphasises the importance of experiential knowledge and implicit learning. Communities of practices are usually defined as '*group of people who share a concern or passion for something they do and learn how to do it better as they interact regularly*'. (Wenger-Trayner & Wenger-Trayner, 2011, p. 1). It is also emphasised that Communities of Practice are united by

- a common theme (in this case: autism or learning disability),
- a community – a group of people who engage '*in joint activities and discussions, help each other and share information*' (here, various communities participants mentioned)
- and have a common or shared set of practices (various advocacy and self-advocacy practices appraised above). (Wenger-Trayner & Wenger-Trayner, 2011, p. 2)

Communities of learning are also characterised by implicit forms of learning and *tacit knowledge* (Duguid, 2005), which are core concepts acknowledged by practice theorists as well (Collins, 2001; Schatzki, 2001; Turner, 1994). Tacit knowledge may be an important realm of skills or know-how that allows advocates and self-advocates to practice advocacy. Skills and information needed for (self-)advocacy may be learned tacitly, for example through shared practices, discussions or just by '*being in the community*'. The know-how of advocacy practices may be more profoundly shaped by tacit knowledge and implicit learning than previously assumed, and their importance may match that of formal education. Future research should provide deeper analysis to explore how the diffusion of knowledge happens within advocacy collectives, and how forms of learning – including implicit forms of learning – shape the way advocates or DPOs work.

Is there a difference between the practices self-advocates do and practices other advocates do as part of their advocacy?'

This question was concerned with historical differences between groups of members of the advocacy movement, such as parents, professionals and self-advocates. Only slight differences appear between what different participant groups do as part of their advocacy. This finding suggests that roles currently occupied dominantly by a specific group of advocates could be potentially occupied by members of another group as well. For example, although common knowledge may suggest that delivering training is something that mostly

professional advocates do, in fact, training and lectures are already delivered regularly by self-advocates with a learning disability, autistic people and parent-advocates as well. This finding may also suggest that historical differences and power imbalances between groups of advocates (such as parents, professionals and self-advocates) are not present purely because a certain group is unable to engage with core practices of advocacy. If the majority of practices integral to advocacy are already done by both disabled and non-disabled members of the movement, then power imbalances within the movement may have explanatory factors outside the presence of the disability one has. It is possible that self-advocates' participation in the disability movement, is hindered by other factors – such as skills and necessary resources. This assumption is also supported by practice theorists' observation that practices may be in hierarchical relationships with one another. For example, Warde claimed that different practices may involve different rewards where '*contrasting understandings, levels of practical competence, and degrees of involvement generate behavioural variation'* (Warde, 2005, p. 147). Indeed, some differences between advocacy practices may explain different 'degrees of involvement' in the disability movement.

For example, while only minimal or generic skills are required for practices like *'attending meetings'*, *'being active on social media'*, '*meeting peers'*, '*writing things up'*, or '*passing on information'*, other practices need solid technical knowledge, for instance '*making videos'*, *'litigating cases'*, '*managing an organisation'*, '*organising rallies'* and *'graphic design'*. Further research could investigate the complex relationship between self-advocates' roles in the disability movement from the perspective of available skills and trainings that enable self-advocates to occupy roles needing more technical knowledge. It is possible that self-advocates may be excluded from certain roles (including leadership roles) not merely because they do not have the potential skills or even experience to occupy those positions, but because formal training, formal qualifications or 'learning from practice' as members of a Community of Practice are not available to them.

Related to skills, different practices may also demand different resources. One can only do practices that they have the necessary resources for. The spectrum can be quite broad: some practices are done with minimal material, financial or human resources, while others are very resource-demanding. For example, while '*writing letters'* require relatively minimal resources, but '*going to conferences'* or '*going to training'* may involve substantial costs for travel, registration fees or accommodation – which may exclude self-advocates or parent-

advocates from the possibility of joining those practices. Further research could focus on internal disparities within the learning disability and autism advocacy movement in terms of available resources. Individuals' income, the availability of paid positions within the movement, and costs of doing advocacy practices (including the costs of 'para-advocacy' practices discussed earlier) may influence strongly the level of involvement of self-advocates within the movement. It is possible that many self-advocates, although they have the will and skills to do advocacy, are hindered from doing advocacy practices for financial reasons or because paid positions at organisations are not equally available to them. It is also possible that available resources including paid positions and technical equipment are not equally controlled by advocates and self-advocates, and professional advocates and parents may still control most available resources. Further research may verify these assumptions.

What are the emerging themes among practices that members of the learning disability and autism advocacy movement do?

The analysis also revealed five common themes across practices which included the previously dominant shorthand for advocacy 'speaking up', but also included other themes such as 'informing and being informed', 'using the media', 'supporting others or being in the community', and 'organisational duties'. This suggests that a significant part of what advocates and self-advocates do are in fact 'para-advocacy' practices embedded in people's everyday routines. Similar to Warde's observation on consumption (Warde, 2005) which is '*not itself a practice but rather a moment in every practice*' (p. 137), it can be claimed that advocacy practices are not always practices themselves, rather moments or actions embedded in other practices. When a self-advocate or a parent of a child with a learning disability goes online to chat with peers, it may be crucial for the advocacy they do, although the activity itself may not be seen as '(self-)advocacy'. The line is often blurred between what is recognised to be part of advocacy or self-advocacy ('speaking up') and what members of the movement do (various para-advocacy practices). These tacitly but regularly done para-advocacy practices include consuming and producing media content, the use of social media, supporting others, or informing and being informed. Advocacy and self-advocacy may also include significant bureaucratic duties.

$$***$$

This chapter attempted to rethink what self-advocacy means in today's disability movement. The analysis of terminology and definitions showed convincingly the lack of consensus about meanings and definitions employed by members of the movement. The terminology used is

107

also highly erratic, making it difficult to rely on language (or linguistic representations) when trying to understand what self-advocacy is.

On the other hand, a practice theory-inspired analysis allowed us to rethink self-advocacy and see its numerous similarities with other forms of advocacy. In fact, the analysis proposed a new definition for self-advocacy which leads the study in a new direction. The disability movement (including the autism advocacy movement and the learning disability movement) may be a Community of Practice or may be composed of Communities of Practices. The implications of this finding and its relationship with other findings of this study will be revisited in Chapter 8.

In the following chapter, the conceptualisation of self-advocacy will be once again looked at by exploring typical routes people follow when they become (self-)advocates. The analysis of pathways to (self-)advocacy will be concluded by a mapping of the distinctive forms of (self-)advocacy within the contemporary disability movement.

5   CHAPTER FIVE – PATHWAYS TO ADVOCACY

BECOMING A SELF-ADVOCATE OR AN ADVOCATE

As noted before, self-advocacy is always partly an individual action, even when self-advocates and advocates work within formal or informal groups. All advocates and self-advocates even as members of organisations retain their own voice, their own identity and own stance about issues important to them. Therefore, when conceptualising advocacy, it is necessary to step closer to participants and explore not only how they define advocacy or self-advocacy or to analyse advocacy practices (presented earlier), but also to assess how they see their own route to advocacy.

Looking at how individual life stories and (self-)advocacy intersect is not new. Much of previous literature paid attention to both collective self-advocacy and the stories of individual self-advocates, for example how individual life stories relate to one's participation in a self-advocacy group (for example Anderson & Bigby, 2015; Goodley, 2000; Shore, 2004; Tilley, 2006a). Other studies explored how the identity of leaders of self-advocacy organisations influences the way self-advocates work within the disability community (Caldwell, 2011). Life stories of non-disabled advocates also shape how advocacy organisations work: for example, parent-advocates' own motivations and views on advocacy changes over time which prompts them to establish or to leave organisations and cease to see themselves as advocates (Balázs & Petri, 2010).

Becoming a self-advocate or starting self-advocacy is an important step in one's life. By asking how one becomes a self-advocate or advocate, it is possible to appraise how advocates/self-advocates recall their own route to advocacy and whether they think there is a point or phase when one 'becomes' an advocate as opposed to someone who is not an advocate. In order to further conceptualise advocacy and self-advocacy, it will be explored how participants see their becoming an advocate or self-advocate. It is assumed that participants' lived realities may influence how they conceptualise advocacy: what type of advocacy they do, how they do it, or whether they do it as part of formal or informal groups.

Therefore, in order to amend the analysis of definitions and practice-based concepts of advocacy /self-advocacy in the previous chapter, in this chapter individual conceptualisations will be looked at by assessing participants' statements about their own routes to (self-)advocacy. The following analysis does not attempt to question or replace the

considerations of the conclusions presented in Chapter 4 – instead, it will be used as a valuable addition to them.

5.1 METHODOLOGY

During interviews and focus groups, a prompt was used to illuminate individual stories and allow participants to talk about how they started to do (self-)advocacy in practice. This prompt also served as an ice-breaker, highly important in an interview or focus group setting (Fielding & Thomas, 2013; Gilbert, 2008; Kitzinger, 1994).

Questions varied depending on the context: 'How did you become an advocate / self-advocate?' or 'Why did you decide to work as an advocate?, 'How did it start?', depending on the participant's background or their personal relationship with the researcher. Following the questions, participants revealed various important details about their motivation, family or other personal backgrounds, and importantly, they expressed very personal views on the role of advocacy/self-advocacy within participants' own lives. Such personal narratives gave important additions to more general or formal definitions analysed in Chapter 4.

Data was analysed by employing thematic analysis: common themes were identified to highlight what advocacy meant for individuals themselves. However, before offering an analysis of routes to advocacy, it is important to note the overlaps between two participant categories: parents and professionals.

The recruitment plan for this study included self-advocates and advocates (including parents and professionals). Altogether in Hungary and in the UK, there were two focus groups and 15 interviews with parents and professional advocates: one focus group (n=4) and six interviews with advocates in autism; one focus group (n=5) and nine interviews with advocates in learning disability. Overlaps between the two categories, advocates in 'learning disability' and advocates in 'autism' have been discussed earlier.

However, there was another overlap between two groups of participants. As stated before in Chapter 3, almost all parent-advocates also did some form of professional advocacy, for example, they were members or leaders of advocacy organisations, they gave advocacy training, they engaged in policy-making etc. In fact, almost all parent-advocates have held paid advocacy positions. Even the one participant who worked outside organisations and had very little income from her advocacy work retained a strong identity as an advocate and trainer in learning disability. Therefore, in the following section, participants' being recognised as 'parent-advocates' did not mean they had no professional experience in

advocacy – it was their parental roles that made them distinct within the broader group of professional advocates. In other words, parent identities were assumed to be central in their approach to advocacy, whilst it was acknowledged that the advocacy these participants do – such as speaking up, running groups, informing the public, supporting families or self-advocates etc. – may be rather similar to what professional advocates do.

Therefore, the following analysis will be arranged around four groups of participants: parents, professionals, autistic self-advocates and self-advocates with a learning disability. Emerging themes will be discussed in each section about specific participant groups' pathways to advocacy. Then, a final analysis will be offered bringing together salient themes from all three participant groups. Finally, at the end of this chapter, based on the discussion, a new, Pathways Model will be offered.

5.2 PATHWAYS TO ADVOCACY AND SELF-ADVOCACY

In this section, the findings of the thematic analysis will be presented. Parent-advocates, professional advocates and self-advocates (people with a learning disability and autistic people) will be discussed separately.

5.2.1 Parents' route to advocacy

At the time of recruitment, seven out of 43 participants (six from Hungary and one from the UK) were recognised as 'parent-advocates', for example, because they were members of or working at an organisation of parents of disabled people, or because they ran websites where they explicitly mentioned being a parent-advocate. During data collection, however, several more professional advocates disclosed close family relationships – including parental roles – with disabled people in the context of their advocacy work. In this section, only data from participants whose parent-advocacy role was publicly disclosed will be discussed.

Advocacy is necessary

Parents' decision to start advocating for their families or for their children starts in various ways. One emerging theme was the diagnosis of their child, which prompted their becoming an advocate. For several parents, becoming an advocate was perceived as a '*necessity'* after diagnosis, for example, because there were no services or support available for their children.

When recalling their route to advocacy, many parents mentioned the reception of the disability diagnoses of their children, which was usually framed as a starting point.

111

I started doing advocacy in 2008 when my son got the autism diagnosis. I think parents [of autistic children] start doing advocacy right when they get the diagnosis. (HU advocate for autistic people)

Notably, when parent-advocates talked about how they started advocacy, it was sometimes seen as the beginning of a journey, with one participant speaking about advocacy akin to a road. This suggests that parents may feel their advocacy is a necessary answer but is not a one-time action or an irregular activity, but rather a long-term commitment.

It was because of my child. Originally, I came from a sciences background, then I was a housewife, and I started doing advocacy exactly because I have an autistic child and I couldn't find services for him. I remember when I thought, 'there must be a way for us' and I started looking up for information to see how others do this. And that's how we stepped on this road: alright, there are no services for us now. But we will make sure there will be services! That's how it started. (HU advocate for autistic people)

Not only the lack of available services but disabled children's conditions were also mentioned as important factors in parents routes to advocacy. Some parents explicitly questioned their child's ability to self-advocate, which was sometimes stated as the main reason why parents needed an advocate for them. The below statement contextualised impairment as essentially disabling to the point when the participant's adult child would not understand the concept of self-advocacy, therefore making it necessary for the parent to advocate for him.

Researcher: *How did you get into this role of an advocate?*
Advocate: *I have got two children. Including one who is… he's now nearly 23, he is profoundly disabled and he also has very complex medical problems. (…) My son cannot self-advocate. He wouldn't even understand what it means.* (UK advocate in learning disabilities)

A particular focus on the perceived deficits of having a learning disability or being autistic were present in other parent-narratives as well. For some parents, there was a common feature of autism which may hinder not only their children but autistic people in general from being able to advocate for themselves. In the following opinion, the reference to autism as a strongly disabling condition was framed as a core reason why organised parent-advocacy was necessary.

112

Well, I think autism is a type of disability where… they [autistic people] cannot speak up themselves. Parents' organisations got founded back then exactly because they [autistic people] cannot always advocate for themselves. (HU advocate for autistic people)

It must be noted that such a deficit-focused view was not shared by all parent-advocates. One parent advocate stated it may not be the impairment of their child that hinders self-advocacy but various environmental factors as well.

Advocacy as collective

Parent-advocacy was framed by several participants as a necessary reaction and *collective effort* to speak up for their children. With the exception of one parent, all parent-advocates disclosed membership or active involvement in parents' groups or other advocacy organisations. For several participants, advocacy started around the time when they met other parents and started working together with them. Here, a second theme is recognised: *parents' organisations*: parents often associate their parent-advocacy as having been initiated within parents' groups. Several parents recalled founding membership in advocacy organisations as a starting point in their work as advocates.

I established and I've been leading the X. Association. My daughter is already over 14. It was simply necessary to start an organisation because no one was speaking for us. Whatever other NGOs were covering was not enough for us... (HU advocate for people with severe intellectual disabilities)

Most parent participants put a strong stress on 'we' in their statements, signalling that many parents think about their advocacy as a collective effort which is essentially carried out together with other parents.

Researcher: How did you start advocacy?
Advocate: We started a local NGO in X. city back in 2014, and that was also when we joined the national umbrella organisation. (HU advocate for autistic children)

Some parents saw the start of their advocacy not at the initial point when their child received their diagnosis but at the time when they started doing collective advocacy. This demonstrates that not all parents see themselves as advocates – the diagnosis of their children is a necessary but not sufficient factor in becoming a parent-advocate.

113

We started our local association at the point when we realised that we cannot help our children on our own and we need to come together, parents. (…) My child had received his diagnosis long before that, but then I had no idea about advocacy and all that. (HU advocate for autistic people)

While many parents continued to work together with self-advocates in formal organisations, support groups and other collective forms of advocacy, it is important to recognise that parents' approach to disability differed from that of self-advocates'. Indeed, medicalised perspectives and a strong focus on their children's impairment may differentiate parents' approach from the core ethos of the self-advocacy movement.

Parents often contextualised advocacy with a strong sense of 'we': the concept of parent-advocacy is often a collective one. This collective identity was further strengthened by the notion of *fighting* for their children, with one participant likening parents of disabled children to '*mother tigers*'. This signals that even if many parents differ in their views from self-advocates, they can still retain a strong identity as advocates who are speaking up for their children.

5.2.2 Professionals' route to advocacy

Advocacy was a paid position for many participants, who were categorised under the label 'professional advocates' to make them distinct from other advocates such as parents or self-advocates. In this category, only those participants are grouped together who were working as advocates or in jobs that included advocacy roles but who did not disclose being a parent of a disabled child at the time of recruitment.

Jobs held by professional advocates in this study varied greatly, partly because of the sheer diversity of jobs in the learning disability/autism movement – but also because of the different cultural and legal backgrounds between the UK and Hungary. For example, whilst in the UK there are statutory obligations to provide professional advocates for families or disabled people who wish to get social services (Care Act, 2014), a similar legal obligation – and the publicly acknowledged and legislated role of an advocate – is non-existent in Hungary. Nonetheless, in both countries, people working in different positions at different bodies saw themselves as professional advocates or professionals whose job included elements of advocacy. Participants in this study had different professional experiences as advocates, for example:

114

- manager and support worker of a self-advocacy group, co-editor of a website on self-advocacy,

- a barrister with specialisation in disability law, legal capacity, non-discrimination etc, also runs a legal clinic,

- CEO of an NGO that does significant human rights-based lobby in learning disability policies, and also runs a resource centre for families about rights and services,

- Founder of a human rights NGO specialised on disability rights and discrimination,

- A professional advocate working under the UK's Care Act 2014,

- Support manager for families with autistic family members at a regional NGO,

- Co-director of a local organisation of self-advocates with learning disability in England,

- Regional manager of a national umbrella organisation in learning disability in the UK that runs advocacy courses, supports numerous self-advocacy organisations,

- Founder of a community initiative and various outreach programmes in a Hungarian city, empowering disabled people and other disadvantaged groups.

Given the diversity of these roles, it is highly informative to explore the common elements (themes) in the narratives of participants coming from so different backgrounds, engaging with very diverse client groups. There were three such common themes in the way participants saw their routes to advocacy.

Advocacy as a job

Several participants had a background in social work, healthcare or similar profession. This theme can be labelled '*advocacy as a job',* relating to participants who saw their advocacy job as a step or station in their professional careers.

> *In the beginning, I worked for an organisation for people with sensory impairments, and even in residential institutions. Then I got into civil society, first at X. organisation and then at Y. NGO where I worked for 15 years, working in disability advocacy all these years.* (HU advocate for people with a learning disability)

Framing advocacy as a job does not mean it does not hold certain values for people. Although participants spoke about their professional development leading up to advocacy, many participants noted that they found the role of an advocate a satisfying one.

> *I left medicine and I was looking for a job, and because I had already worked in health and disability, I was looking for that kind of thing. And when I saw the advocacy job it just appealed to me, and I applied and when I got the responses from them that I was*

115

the one I was very happy about it and they were very keen to have me. (…) also, it has always been important to me to give people a voice even before, so any time when I worked with patients or clients or any kind of support work, the patient voice has always been primary to me in any healthcare role. So, I took very naturally to advocacy. (UK advocate for autistic people)

Giving people a voice or supporting them beyond the framework of traditional social work or healthcare were mentioned as motivating factors in participants' concept of professionalised advocacy. The following statement implies that advocating for someone may not be the same as supporting someone.

I did my MA degree in social work. (…) How I became an advocate…? it took me time to realise that social work is not exactly what I thought it would be, what I was thinking of was more advocacy so that's how I became an advocate. (UK advocate in learning disability)

For some participants, the inspiration to start working as professional advocates was related to certain life experiences such as getting to learn about advocacy initiatives abroad or getting acquainted with experienced advocates.

I started working with non-verbal people already back in 1995 and we were thinking a lot about this, how to do more, because people, I mean society just didn't care about the whole issue. I wanted to do more. Then someone from the US found me through friends, someone who spent time here with a Fulbright [scholarship] and they were looking to establish an organisation here. I spoke English very well, had spent time in the US, I knew American culture and it turned out we can work together well. And then we established X. organisation in 1996. (HU advocate in learning disability)

Affinity to oppressed groups

Holding a professional position in disability advocacy does not mean participants see their work purely as a professional matter. In fact, participants often interpreted professional advocacy as strongly related to their personal history or individual circumstances.

The second emerging theme is labelled *personal affinity to oppressed groups*. Empathy and willingness to support vulnerable or disadvantaged people were commonly mentioned in all interviews and focus groups, but when asked about routes to advocacy, several participants explicitly emphasised the importance of their fundamental beliefs. For several participants,

such beliefs were rooted in the Christian tradition, which got an explicit emphasis when they were speaking about their decision to engage with disability advocacy.

> *I come from a background of Christian ministry. I was with the Salvation Army as a full-time officer. (…) I feel very strongly when I see inequality when I see some people have power and other people don't and there are structures that reinforce it. So, it's access to public goods, public opportunities that should be shared and open to everyone. And power. So, equality and commitment for the vulnerable. Salvation Army is very much about that, its whole ethos is about people who live on the margins who are not seen, not heard. (…) So, all of that stayed with me and I was looking for something else where I could bring those values but without being locked into the belief of Christian ministry. And stumbled across that organisation, which was looking for someone to join the management team*. (UK advocate in learning disability)

Others stressed that not only their religious background but also their own experiences of discrimination or belonging to another minority group were important factors that made them willing to work as disability advocates. Here, a shared experience of oppression – both racial oppression observed in South Africa and personally experienced oppression as a gay person in the UK – shaped one's understanding of and affinity to learning disability advocacy.

> *My background is theology, I trained to be an Anglican priest and I was very lucky to spend a year when I was younger to look in South Africa, during the apartheid period and became very interested in oppression and liberation theology and understanding how socially excluded groups have a voice, so that was all being the passion of mine. (…) My passion comes in the fact that part of the experience of what I learned in South Africa but also as growing up as a gay man so you understood what it meant to be excluded from… the norm. That's where my empathy is with people with a learning disability that essentially you understand that people because they are slightly different that society doesn't really understand or want to include them. So that's the background.* (UK advocate in learning disability)

The emphasis on personal beliefs and shared experiences of oppression – as in the views of the gay participant – demonstrates powerfully that personal choices in professional careers may also be shaped by personal factors such as identity or religious beliefs or other values relating to a continuous commitment to ideals disability advocacy is associated with.

117

Family background in professional advocacy

The third theme in professionals' conceptualisation of advocacy was advocates' family relationships with a disabled person. Indeed, a decision to work as a professional advocate may be influenced – at least partly – by people's personal, family backgrounds.

At the time of recruitment, it was unknown to the researcher that several professional advocates had close family members with disabilities, however, during interviews and focus groups many of them mentioned disabled family members such as their children, siblings, uncles and members of the wider family. In the following narrative, having a relevant educational background is accompanied by a family background that is framed as decisive in participants' narratives.

> *I did a degree in learning disabilities and health originally, but what put me into there is my uncle has got Down's Syndrome and autism. And then I came into that field kind of accidentally because I wanted to work with children and then I ended up thinking I don't really like children [laughs] and I ended up working with adults. (UK advocate for autistic people)*

Several narratives in this study demonstrate that for professional advocates paid advocacy positions may often mean more than just a job they are holding: their relationship and commitment to disability issues had started before they became professional advocates for disabled people. For one participant a disabled stepbrother was important in her narrative when she recalled her route to advocacy. Here, 'not fitting in' is framed as an experience that the participant shared with her stepbrother.

> *The family where I was placed had a child with severe intellectual disability and other disabilities and the programme I worked in was to encourage to make yourself part of that family, to call the parents Mum and Dad and to regard their children as your siblings. So I acquired a little brother with an intellectual disability (…). How I became [an advocate]…? I was a child in a large immigrant family in X. so I was always looking after younger children. (…) So I'd been brought up into a kind of caring role. So that was one of the factors in it. The second thing was that we were both odd kids. Neither of us quite fitted in.* (UK advocate in learning disability)

Family background sometimes became important only after someone decided to work as an advocate. Some participants already had significant experience in disability advocacy when their disabled child was born or when a member of their family got a diagnosis. This –

118

perhaps seemingly unusual – route to advocacy also implies that changing family relationships may potentially influence how professional advocates work and how they see their role in advocacy.

> *I have five children including one who has Down's Syndrome. He is eight now and goes to a special school, so my experience in advocacy is that of a parent's. But I used to work at X. organisation for a year, so I had experience in advocacy from a period when I hadn't had a disabled child. I am also a special teacher and have been training people on advocacy as well, and I also used to work in public administration on disability policies, with disabled people's organisations before I got involved as a parent.* (HU advocate in learning disability)

The two latter themes in accounts – affinity to oppressed groups and family background – are strongly value-related and also demonstrate the diversity among professional advocates. Perhaps unsurprisingly, personal values do matter for many professional advocates – in fact, it is the assertion of this study that family relationships and personal beliefs are often central to advocates' views and it is highly simplifying to see them purely as people who are doing their jobs.

5.3   BECOMING A SELF-ADVOCATE

Becoming a self-advocate was an important step in participants' lives. To be acquainted with other self-advocates and to be involved in self-advocacy was acknowledged to bring about meaningful changes in people's lives. It is also asserted across several studies that joining a self-advocacy group is a major decision that may impact the lives of people with learning disabilities in various ways (Clarke et al., 2015; Goodley, 2000; J. McNally, 2005; Spedding et al., 2002).

Indeed, several self-advocate participants emphasised the importance of the point when they started advocacy. However, despite the importance of the initial introduction to self-advocacy, participants emphasised different facets of their experiences and feelings. For example, self-advocates with a learning disability and autistic self-advocates did not always share the same views about their pathways to self-advocacy.

There were three different themes that emerged across narratives of self-advocates: *diagnosis as a starting-off point* to self-advocacy; advocacy as a *necessary reaction* to barriers (this theme resonates with a similar theme in parent-advocacy); *and meeting other self-advocates or belonging to the community*.

119

Only one testimony was outside these three themes, representing a somehow atypical route to advocacy: one participant became an autistic advocate because she was invited to deliver training in a church community.

> *I was actually approached. So, I didn't initiate any of this. And it's basically... X's son is autistic and she felt quite strongly that actually there is a quite big 'we can do' trope at the church because especially in the Church, it's 'this is the way we do it, this is the way it's always been done', so that's a way to kindly challenge people…* (UK autistic self-advocate)

The above quote demonstrates that self-advocacy may start when one gets approached, motivated or given opportunities by others. This signals the importance of social factors and social relationships, which may have major roles in how or why someone becomes a self-advocate.

Diagnosis as a starting point

Nearly all autistic participants stated that receiving their autism diagnosis was a major starting point in their self-advocacy – similar references to diagnosis were not found in the testimonies of people with a learning disability.[19] For one Hungarian autistic self-advocate, although she had had previous contacts with disability advocacy, getting an autism diagnosis was a pivotal moment that set her on seeing herself as an autistic self-advocate. In the following quote, autism diagnosis is compared to another disability diagnosis.

> *I had already been around disability advocacy, even before my autism diagnosis, because I also have a visual impairment and a physical disability. (…) I realised that my problems related to being on the [autism] spectrum are far bigger than my visual impairment or my physical disability.* (HU autistic self-advocate)

For another autistic participant, autism seemed far more important than other diagnoses she had received. Here, self-advocacy was conceptualised around being a 'performer' who constantly tries to become more herself by being autistic instead of someone who pretends to be neurotypical. Significantly, in the following statement seeking information about autism is a preliminary step to advocacy and is central to one's self-understanding.

---

[19] All autistic self-advocate participants in this study received their diagnoses in their teenage years or even later, in their 20s or 30s. Narratives about receiving a diagnosis may be different for self-advocates who were diagnosed with autism as children.

Yeah, well I was diagnosed with dyslexia when I was about… well, dyslexia and dyspraxia when I was about 35 (…). But I still knew things weren't going very well, I kind of had mental health problems most of my life so I kept going back to a doctor and I was diagnosed at the age of 39 with autism. So that kind of just completely changed my world and I got obsessed with it and started reading everything that I possibly could about it and thinking about everything, self-diagnose… diagnosing everyone around me [laughs] (…) I performed a neurotypical person in my whole life and it is totally innate within me [laughs] and because I did it for 39 odd years and I guess my self-advocacy in a way is kind of make myself more myself [laughs]. More autistic. (UK autistic self-advocate)

Seeking information such as reading about autism are recurring topics in several interviews, usually framed around the reception of autism diagnosis. Connecting with other autistic people is seen as highly formative in self-advocates' narratives about their route to advocacy, with one self-advocate calling it an *'epiphany moment'*. The below interview signals importantly that for many autistic people self-advocacy starts with an autism diagnosis, which also enables them *'to find a community'* they belong to, where they can also share their own experiences – a *'form of peer-advocacy'*.

It probably started when I first got self-diagnosed and I had that sort of... epiphany moment of WOW, all this stuff plus me... and I went online and I looked at things, and I already knew a lot about autism and I guess I was already aware of some of the things out there and people like, I suppose Temple Grandin and the big names of autism, but I saw not so many actual autistic people, so I guess that came later when I self-diagnosed that I learned, I guess I sought out more autistic adults that have shared experiences, and that was something I read a lot about, online or on Twitter or on different blogs. In a way that was a form of peer-advocacy, just people sharing their experiences in a way that really resonated with me. Particularly as someone who got diagnosed very late, the sense of isolation was strong and finding community for the first time, finding people who shared those experiences, so that was HUGE [with emphasis], that was massively important to me. (UK autistic self-advocate)

Speaking about diagnosis was often contextualised along with meeting other autistic people, before or after the diagnosis. Receiving an autism diagnosis may mean not only going through a medical assessment but may also be akin to membership in a community where others with similar problems and identities belong. The last statement's emphasis on 'shared

121

experiences' in the (online) autistic community stands in stark contrast with the period before the diagnosis which is described with the word 'isolation'.

Self-advocacy as a necessary response

Several self-advocates talked about a 'necessity' that prompted them to start advocacy, for example, because they saw other advocates such as parents or professionals not representing them. Indeed, self-advocacy was seen by several participants not only as a *possible* answer to difficulties or barriers but also as a *necessary*, much-needed step that people take because what they see is 'not enough'.

> *I only got my autism diagnosis recently, only a couple of years ago. Then I went to meet other autistic people and we realised that we are represented on the one hand by professionals and on the other hand by parents. We felt that's not enough. And then it started from there… and since that time I have started to organise advocacy myself more regularly.* (HU autistic self-advocate)

Other autistic participants found self-advocacy was a needed reaction to barriers because they felt solidarity and responsibility for their peers who should not go through similar difficulties. Similarly to the previous opinion, stepping up as a self-advocate is explained by references to the broader group of autistic people.

> *I do think it is important that I do autistic advocacy, just like other people have said this, that I just don't want to see other people going through the same suffering as I had to.* (HU autistic self-advocate)

Similar views were also expressed by self-advocates with a learning disability – according to one British self-advocate, it is the systemic marginalisation, ignorance and prejudice against his peers that made him want to pursue self-advocacy.

> *The reason why I became a self-advocate is I want to speak up for people with a learning disability and I believe people with a learning disability should be treated equally like everyone else. The bad thing is that the public has a negative attitude towards people with a learning disability. And it's a disability that one of those disabilities that are hidden and that's why a lot of people don't know about learning disability. (British self-advocate with a learning disability)*

Becoming an autistic self-advocate was sometimes mentioned as a necessary transition from one social role to another. In the following statement, the role of an 'accidental activist' is

changed into that of a self-advocate's who represents peers in a partnership board of a local charity.

> *I don't think anything brought me to the field, basically my own lived experience, having to step up was a necessity really and that largely comes from being diagnosed at the age of 25, having got into all the various schools and university and then into work, coming into some difficulties, and then in X. where I lived was a social group that was run by the mental health services for pretty much a decade and me and two other women joined (…) So what happened was that the group was closed and because I have the capacity and out of necessity I needed to step up. (…) So I transitioned into, from the position of an accidental activist to the collaborator on the XXX partnership board and then worked as a strategic advisor to the board for a year.* (UK autistic self-advocate)

In the above interviews with self-advocates, starting advocacy was often framed as becoming part of *'something bigger'*. Advocacy may also be seen as a necessary step in someone's 'personal journey' when facing barriers. In the words of one British autistic self-advocate: '*it was purely based on my personal journey and my lived experience that I am where I am*'.

Meeting peers

The above two themes – diagnosis and necessary response – were important themes in nearly all autistic self-advocates' routes to advocacy, but they were not featured in the accounts of all self-advocates with a learning disability. However, a third theme *'meeting peers'* was featured in the accounts of both autistic self-advocates and participants with a learning disability.

'Meeting peers' did not mean necessarily that all self-advocate participants formally belonged to a group or organisation. For example, although this was a recurring theme for all self-advocate participants, group membership or belonging to formal organisations was not mentioned by most autistic participants, whereas for self-advocates with a learning disability, meeting peers always took place within a formal group or self-advocacy organisation.

Indeed, for participants with a learning disability self-advocacy was intrinsically related to formal group membership or to an NGO that people mentioned as their 'entry point' into self-advocacy. Similar references to NGOs or formal group membership were rarely made by

123

autistic participants. On the other hand, nearly all of them made references with emphasis to a broader 'autistic community'. This broader 'autistic community' was often mentioned along with the internet where much of the correspondence takes place. Several autistic participants recalled that they 'started reading things about autism' on the internet, and then proceeded to get in touch with peers by email or on social media. This implies that in autism a broadly defined autistic community may be more salient in people's lives than formal memberships in NGOs or self-advocacy groups.

Nonetheless, for self-advocates with a learning disability, the concept of self-advocacy was inseparable from the self-advocacy group they were members of.

> *I don't remember when I started, but I have been a member of several different [self-advocacy] groups here at X. organisation.* (HU self-advocate with a learning disability)

In the interviews, the names of organisations that run learning disability self-advocacy groups were mentioned regularly in the context of participants' routes to self-advocacy. In participants' narratives, there was often a strong sense of loyalty to groups or organisations, for example, self-advocates often recognised opportunities offered to them by organisations. For example, sometimes membership in a self-advocacy group meant self-advocates had an opportunity to become leaders and work closely with parent-advocates.

> *I have been a member of the X. organisation for 11 years. We are going to start a new [self-advocacy] group next month which I will be leading as well.* (HU self-advocate with a learning disability)

Membership in a self-advocacy group may also bring other benefits. In the below statement travelling overseas is clearly framed as a benefit of the membership in an organisation.

> *I got into this whole self-advocacy in October 2008. Then I even started working here in 2012, and recently I became the co-manager of the organisation. Next month I will be travelling to the USA together with our [parent-advocate] president.* (HU self-advocate with a learning disability)

The importance of an invitation or other external motivation to join self-advocacy was also discussed. Here, the views of two British self-advocates demonstrated that disability organisations may be able to offer viable alternatives to people with a learning disability: potential support, salaried work opportunities and the chance to meet peers make it attractive to become self-advocates in a formal organisation.

124

Researcher*: How did you guys start advocacy?*

Self-advocate 1*: My Mum and Dad are not getting any younger so they decided to get a care manager so we can talk about the future and how it's going to work out. So he said to us 'have you heard of X. organisation?' We said 'No.' And he said 'they do this and this' and we said 'okay, go down, see what they do' and we went down there and done a course and also at that time there were speaking-up groups and I joined with XY so then he supported us to understand different laws and finding people and how to meet people and so I said 'that's what I want to do'… and we help people with a learning disability to be able to do speaking up and have their voice, really. So that's how I done it.*

Self-advocate 2*: Yeah, I was in a residential home, got put there by no choice really, and people I was living with went to X. organisation and they asked if I heard of it and I said no, I didn't have no idea so yeah, I went to X. and I have been with X. organisation for 13 years. I got supported at first and then yeah, I done different courses and met loads of people old and new people through X. and I work for X. now.*

(UK self-advocates with a learning disability)

As the above views demonstrate, membership in or working at an organisation were often accompanied by a strong sense of peer support for self-advocates. Indeed, the sense of peer support was strong in participants' narratives. Several self-advocates expressed that they were ready to reach out to or speak on behalf of other self-advocates. In fact, one participant started off building a national network of self-advocacy groups which he recalled as a pivotal moment in his career as a self-advocate.

I had to learn the hard way… building my own career up, and writing about 400 letters, all handwritten, four pages long each, that's how I started self-advocacy… and I spent my own money and paid for the postage. This was before computers. (UK self-advocate with a learning disability)

Indeed, many self-advocates claimed the very reason why they decided to take on self-advocacy roles was their wish to support others and pursue broader societal changes. This strong sense of solidarity and stepping up for universal values such as equality is similar to the statements parents and some professionals made earlier, who also claimed advocacy was based on values.

125

5.4 DISCUSSION

Data demonstrated several emerging themes in participants' narratives about their routes to advocacy. These themes help to understand advocates' and self-advocates' conceptualisation of advocacy.

Parents often see advocacy as a *necessary answer* to the lack of services and support available for their children. Parents – including whose children have reached majority age – may see their children unable to self-advocate, which prompts them to continuously advocate for them. This perceived inability to self-advocate has been present in the parents' movement for a long time, both in learning disability and in autism (for example, Bylov, 2006; O'Byrne & Muldoon, 2018; Waltz, 2013). Consistently with previous research (Milton, 2010), parents may also see the start of their advocacy as the beginning of a journey. Parents also contextualised advocacy as *collective action* whereby they work together with other parents or they join an organisation – although some parents may prefer doing the bulk of their advocacy alone. This finding is also consistent with previous studies (Russell & Norwich, 2012; Ryan & Cole, 2009) where parents of autistic children may find their social roles as parent advocates strengthened and valued among other parents. Figure 5.1 presents parents' routes to advocacy, along with a process line where arrows signal the 'road' or 'journey' metaphor several participants used when talking about their work as advocates. The vertical dotted line represents the decision to start advocacy, although it is also assumed that such a decision may not always be conscious or pinpointed at one actual life event.
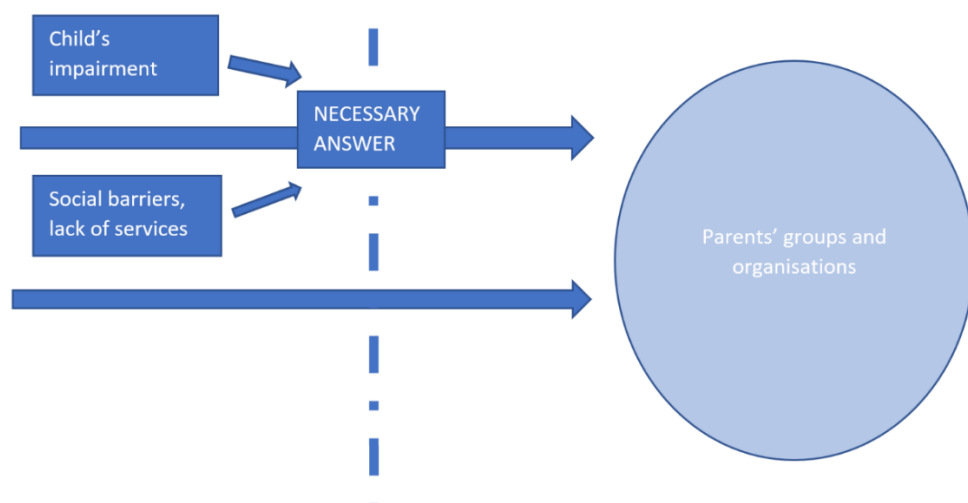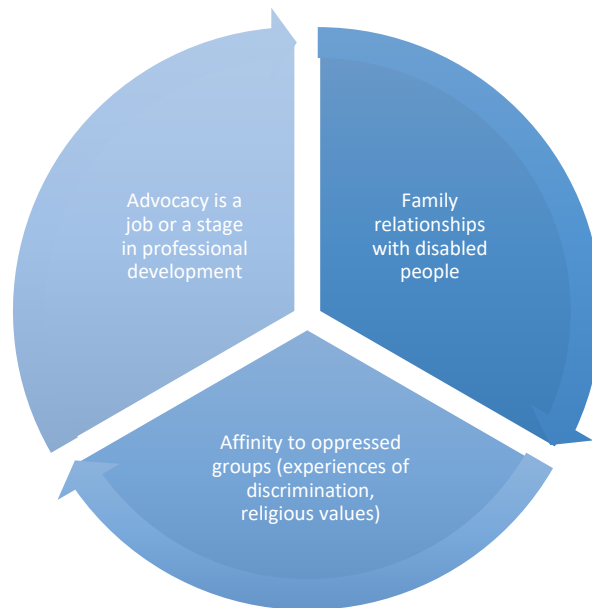

Figure 5.1 Parents' routes to advocacy

Although some parents stated that their child's inability to self-advocate prompts them to do continuous advocacy, this view was not shared by all parents – others made no reference to this factor or disagreed by pointing out that one's limited self-advocacy may be caused by environmental factors. This debate among advocates – also mentioned in previous research (Ryan & Cole, 2009) – is akin to a medical (impairment-focused) versus social (barriers-focused) model approach. Participants' views in this study suggest that parent advocacy can be both and it cannot be pinned down to one model of disability. Some parents retain a more deficit-focused, largely medical understanding of their children's disability, whilst others maintain a social model approach where they recognise the importance of social barriers as disabling factors. It is also possible that the two models be present at the same time in one parent's narrative. Previous research also showed that this variability of how parents see their children's disability may be a subject to several factors, such as stigma or available strategies to de-stigmatise their children (Russell & Norwich, 2012).

Similar to parents, professional advocates had various understandings about their work as advocates. Many professional advocates mentioned advocacy *as a job* or a stage of their professional development. Others conceptualised advocacy around their *personal beliefs* such as Christian traditions or deep, personal commitments to tackle societal disparities – importantly, for some participants, such commitment comes from personal experiences as a member of another oppressed group. Furthermore, for several professional advocates *family relationships* to disabled people is a core part of their narratives about their professional advocacy jobs. This finding highlights that categories set by scientific traditions or shaped by the public discourse – such as the division between parents and professionals (Bylov, 2006; Milton, 2010; Walmsley et al., 2017; Waltz et al., 2015) may not always be so adequate in people's lives.

Contrary to parents' routes to advocacy, professionals' decision to do advocacy is not visualised as a process but rather as a cyclical understanding of people's professional advocacy work (Figure 5.2). Professional advocates, similar to parents' and self-advocates, may decide to do advocacy and may also decide to leave their advocacy jobs. However, while they work as professional advocates their underlying concepts of advocacy are continuously present: all professional participants emphasised either their family background or their personal beliefs/values, or both when they explained their work as advocates.

127

Figure 5.2 Professional advocates' conceptualisation of their jobs

The concepts self-advocates employ regarding their routes to advocacy retains some similarities to the concepts of parents and professionals. Here, three themes were identified (Figure 5.3 – yellow represents autistic people, blue represents people with a learning disability). Some self-advocates started advocacy around the point when they received their *disability diagnosis* – this theme appears to be specific to autistic people and less relevant to self-advocates with a learning disability. Diagnosis – sometimes preceded by a self-diagnosis – is seen as a powerful experience, an 'epiphany moment' which allows autistic people to enter a broader autistic community where they exchange information, share stories, connect and meet each other. This communal experience is called 'peer-advocacy' by some participants. However, belonging to an autistic community is not mentioned in a formal organisational context: the boundaries, rules and membership of this community are unclear, and members of this community often interact through the internet.

The reason why people start doing self-advocacy brings a second theme: self-advocacy was seen by many participants as a *necessary reaction* to barriers. This theme was present in the narratives of both groups of self-advocates. 'Necessary reaction' was mentioned to not only in the context of *barriers faced by individuals* who may wish to self-advocate for themselves. Many participants recognised that such *barriers are systemic* and present in the societal level impacting the lives of their peers. This implies that many people wish to speak up because they want to prevent their peers from having to go through the hardship they experienced.

Seeing parents or professionals speaking up on behalf of disabled people was also perceived as a factor that makes it 'necessary' for people to start advocacy controlled by autistic people.
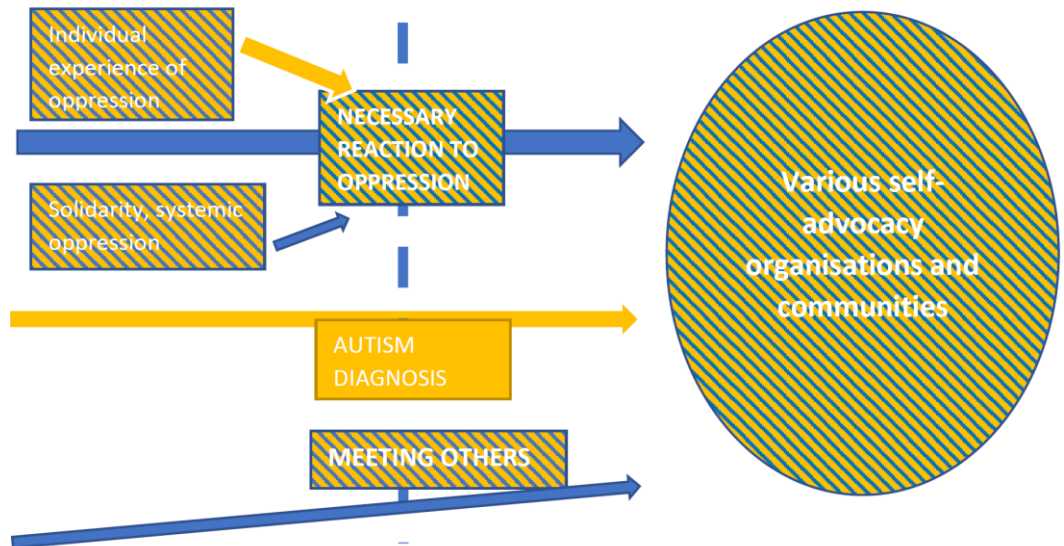
Figure 5.3 Routes to self-advocacy (yellow: autism; blue: learning disability)

A final theme for self-advocates was *meeting others*. Self-advocacy gives an opportunity to meet peers which is valued by all self-advocates. The exchange of information and support was valued benefits of meeting peers and joining self-advocacy groups – this finding is consistent with previous research (for example Anderson & Bigby, 2015; Bigby, 2015; Goodley, 2000; Tilley, 2006a; Tilley, 2013). However, there were marked differences between the two groups of self-advocates in this study: while all self-advocates with a learning disability framed their self-advocacy as a collective effort within formal organisations or established self-advocacy groups, such emphatic reference was not made by autistic participants. Self-advocates with a learning disability always mentioned the name of the organisation or actual self-advocacy group they were members of, but such organisations did not feature in the accounts of autistic people. Autistic participants often made reference to a broader 'community' of autistic people, to peers, 'others' who they often met online etc. At the same time, autistic advocates' emphases on the importance of the autistic community were similar to people with learning disability: the autistic community gives them support and the various opportunities to learn and be with others.

The role of the internet in forming a less formal autistic community has been discussed in literature (Benford & Standen, 2009; Blume, 1997; Brownlow & O'Dell, 2006; Davidson, 2008; Dekker, 1999; Parsloe, 2015; Waltz, 2013). However, how online communities relate to offline forms of autistic advocacy, has been largely ignored in academic research with few exceptions (Trevisan, 2016). Findings of this study suggest that a large part of autistic self-advocacy is carried out by autistic people on the internet or with a strong reliance on Internet-based tools – further studies should look at the relationship between online and offline forms of autistic advocacy.

<div align="center">***</div>

One of the aims of this chapter was to further conceptualise advocacy and to identify a common concept that is inclusive of the various forms of advocacy and self-advocacy. Concepts of advocacy were looked at precisely because novel forms of advocacy and self-advocacy are becoming popular, and previous understandings of self-advocacy – mostly rooted in the traditions of learning disability self-advocacy groups widely discussed in literature (Flynn & Ward, 1991; Goodley & Ramcharan, 2010; Goodley, 2000; Goodley, 2005; Ledger & Tilley, 2006; Tilley, 2006a; Tilley, 2006b; Tilley, 2013; Walmsley, 1993; Walmsley, 2002; Ward, 1998) – seem to have a limited capacity to fully describe contemporary trends.

The analysis of participants' routes to advocacy has revealed important elements of how advocates and self-advocates conceptualise contemporary advocacy.

In the following section a new, Pathways Model will be offered to explain and visualise what typical pathways are available to potential self-advocates within the learning disability and autism advocacy movement. The Model will build on the conclusions of this chapter and also findings of Chapter 4. The Pathways Model will also attempt to tackle some of the contradictions described earlier in Chapter 4 when definitions of advocacy versus self-advocacy were found to be erratic, lacking consensus among members of the movement. The Pathways Model will also offer an answer to the original research question of this study ('What is the position of self-advocacy in the contemporary disability movement?') by showing typical routes and organisational forms of self-advocates within the learning disability and autism advocacy movement.

5.5 A PATHWAYS MODEL OF SELF-ADVOCACY

Difficulties in trying to conceptualise advocacy and self-advocacy do not mean that a mapping of learning disability and autistic advocacy is impossible. In fact, the fuzziness of

concepts gives an opportunity to step away from previous viewpoints and develop a Model that can be descriptive of the learning disability and autism movement whilst respecting the various opinions and individual concepts described above. What follows is a '*Pathways Model*' (Figure 5.4) that offers an understanding of the main routes that autistic people and people with a learning disability follow when they start doing advocacy/self-advocacy. To a certain extent, the below Pathways Model can also be descriptive of the pathways that other members of the learning disability and autism movement – family members, carers, professional advocates etc. – may follow when they wish to advocate.
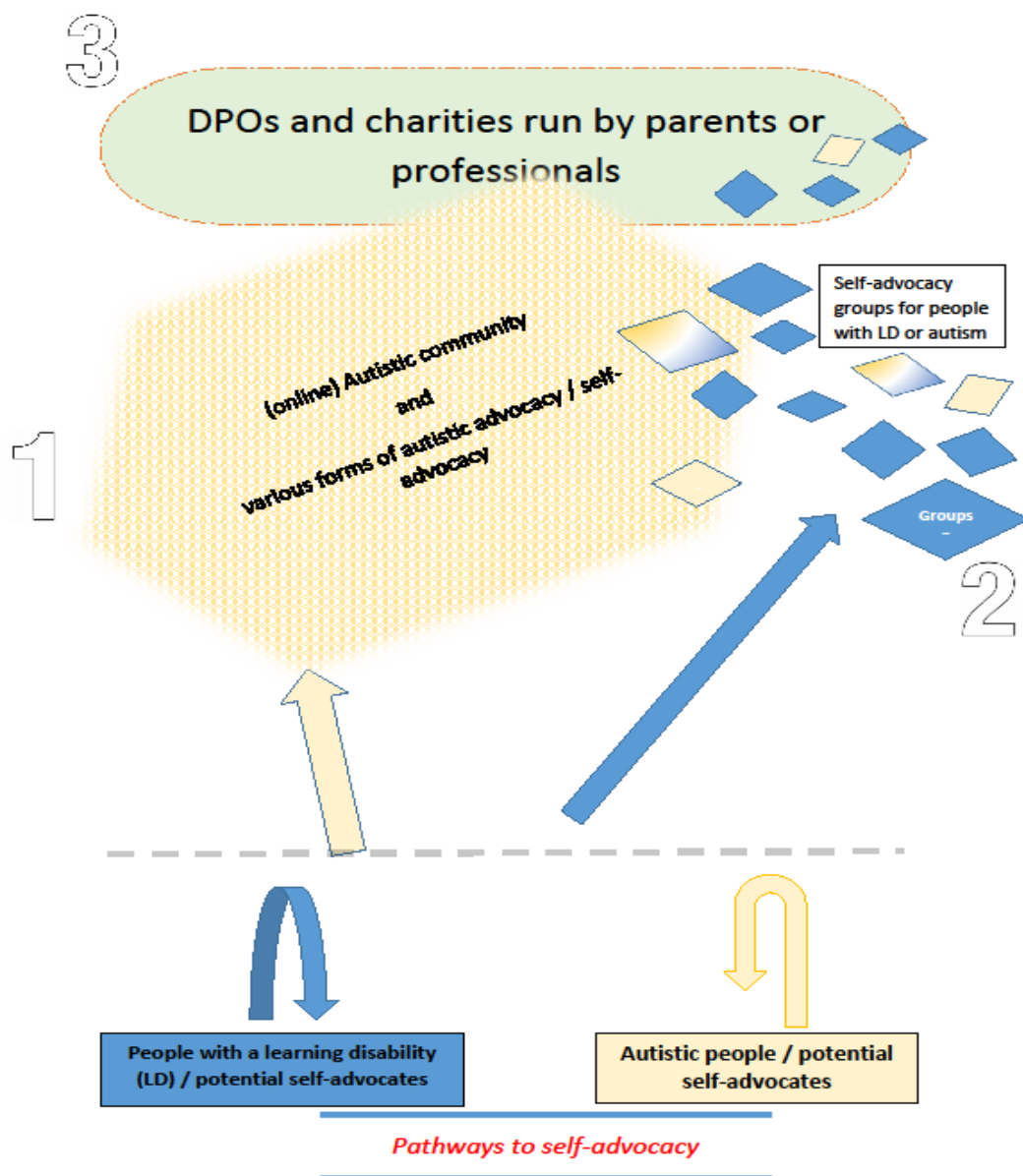

Figure 5.4 Pathways Model to Self-advocacy

131

The Pathways Model offers a line which represents the point where one 'becomes' an advocate or where individuals enter the world of advocacy. This line, however, is certainly not always one single moment or even a conscious decision: many participants recalled that the starting point of their advocacy / self-advocacy was either when they received their disability diagnosis or when they joined or formed a group with their peers while others stated it may not even be a conscious action when they advocate, although they certainly see themselves as advocates. People may turn back and decide not to do advocacy or engage with or join advocacy groups. Therefore, the starting point is always individual and may not even be acknowledged by advocates easily, for example when they are 'not aware' that they are advocating or when they lack the 'reflective knowledge'. What follows is three different pathways people may follow, which are numbered in the chart.

Number 1 is labelled 'Autistic Community' with various forms of autistic advocacy; Number 2 is formal self-advocacy groups within or without charities or umbrella organisations; and Number 3 is charities, umbrella organisations or disabled people's organisations (DPOs) run by professionals, parents or representatives of other disability groups. In the chart, autistic people are marked with yellow while people with learning disability are marked with blue colour.

Number 1

Most autistic people, when start practicing advocacy, become acquainted to a broader autistic community (Number 1). The suggestion that such online autistic community(ies) may be drivers of the advocacy movement has already been made in literature (Dekker, 1999; Silberman, 2015; Sinclair, 2005; Waltz, 2013). Here, it was found once again salient in participants' narratives.

This (online) autistic community does not have formal membership and is not formally led by anyone – on the chart, this is marked by a spotted pattern and no continuous boundaries to the diamond-shaped community. The community is composed of members however, the membership is not formal. Nonetheless, people see themselves part of this community (an important theme featured in personal routes of autistic participants), and they are in touch with several other members of this community. Entering and leaving this community may not be an exact and formal, or even conscious decision – for example, one may only be loosely connected over a period of time then become more active again.

132

All activities in this form of advocacy are carried out by autistic people who may also have non-autistic (neurotypical) allies: people they work together with as part of the advocacy they do. Despite the lack of formal leadership, this type of advocacy may still be *owned* and shared mostly by autistic people who decide autonomously about the actions they take and the opinions they form. This community relies heavily on the use of the internet and various forms of social media and other applications such as chat rooms, bots, video and voice-call software etc. Therefore, the chart marks the community as '(online)', in parentheses – parentheses signal that not all activities and relationships between members are done online because autistic advocates also interact offline.

Number 2

Number 2 in the chart shows formal self-advocacy groups and self-advocacy organisations in various sizes of squares. Squares (groups) symbolise the numerous groups and organisations in the UK and in Hungary (and elsewhere) that work with and for self-advocates. Most squares are displayed in blue to mark that such formal self-advocacy groups are usually run for members with a learning disability – however, to mark that many self-advocacy groups are composed of autistic people, or others not necessarily identifying with any of the two main groups (autism and learning disability), few squares are coloured in yellow (for autistic people) or in gradual mixed colours (for mixed groups). The types and sizes of these self-advocacy groups and organisations are different: some of them are independent groups, others belong to a network of self-advocacy organisations, and some groups are run by other organisations such as big charities, national umbrella organisations, social services or DPOs. Some groups may only have few members, others may be much bigger. There are several studies and typologies developed by researchers about these formal self-advocacy organisations (for example Crawley, 1988; Goodley, 2000; Tilley 2006a) documenting the various ways self-advocacy groups for people with learning disability are managed.

There are also many similarities across self-advocacy groups. For example, most self-advocacy groups are usually helped by paid support workers and the bulk of the work members do together is done offline, during meetings, training courses and various social events. As noted by several authors, joining self-advocacy groups often gives members opportunities to find friends, develop social contacts, to do 'things' together including social and cultural activities and also to learn and develop new skills (for example Anderson & Bigby, 2015; Chapman, 2005; Docherty et al., 2006; Goodley, 2000; Spedding et al., 2002). In

133

this regard, peer support is an equally important aspect of these groups, similar to the way autistic advocates see it important to be working together with members of the autistic community. Finally, such groups may or may not be managed by self-advocates themselves. Some self-advocate participants working in groups were co-directors or vice-presidents of formal organisations, but this is clearly not applicable to all self-advocacy groups.

Number 3

Finally, Number 3 in the chart marks organisations largely led and controlled by professionals or parents or members of other groups of disabled people such as people with a sensory or physical disability. There are both local and national-level organisations belonging to this part of the chart. They can be big charities similar to Mencap or the National Autistic Society in the UK, or national umbrella NGOs such as the EFOESZ (National Organisation of People with Learning Disabilities and their Supporters) and AOSZ (Hungarian Autistic Society), but they can also be regional or local organisations that support disabled people or families: advocacy is often part of their agenda. Characteristically, such established organisations usually have several employees and are led by professional teams. They also run self-advocacy collectives, in Goodley's typology (2000) these are 'divisional self-advocacy groups'. In fact, in Hungary, all self-advocacy groups for people with learning disabilities known to the researcher operate within one of these 'big organisations' controlled by parents and professionals.

Such charities and DPOs may also be led by other groups of disabled people, especially when they work on a cross-disability basis, representing various disability groups such as people with visual impairment or physical disability etc. These charities occupy a somewhat central position in the Model in the top of the 'map' of advocacy, mostly because typically these national charities and national DPOs work the closest to governments or the international advocacy movement. It is also these national umbrella organisations or big charities that are the most likely to connect with international organisations and engage with disability human rights instruments such as the CRPD (Gombos, Kovacs, Szollosine, & Tapolczay, 2010; Meyers, 2014; Meyers, 2016). Notably, members of the autistic community can also be active in these organisations, for example as members, affiliated advisors or even hired employees – this is marked in the chart by a slight overlap between Number 1 and Number 3.

***

The Pathways Model attempts to be a heuristic device to aid our understanding of contemporary self-advocacy. It avoids trying to pin down one single concept or definition for self-advocacy. Instead, it maps different, typical forms of self-advocacy by autistic people or people with a learning disability.

The model, however, is far from perfect, and there can be members of the advocacy movement who would not fit into this model. There can also be advocates or self-advocates who would refuse to agree with this model, for example, because it gives no explanation about certain forms of advocacy they do. For instance, one such form is when autistic people establish a consultancy and give training on autism, not calling themselves advocates while speaking both about their experiences and complex ideas on services, disability politics and policies or human rights. There are also human rights NGOs, watchdogs and other human rights bodies which are relevant in the context of advocacy – for example, they monitor services, do strategic litigation or submit legislative proposals – but they are not displayed in the chart. Finally, there are forms of political representation, for example, the previously mentioned role of a local councillor with a learning disability which is clearly a distinct form of (self-)advocacy, however, the Pathway Model does not cover public bodies and authorities.

The Pathways Model captures some of the typical ways self-advocates and advocates may choose from when they wish to advocate, and it also includes some environmental factors (organisational forms) that influence people's decisions. In this regard, the Pathways Model displays structures such as organisations, bodies and communities which are composed of people, actors with an agency and an opportunity to make decisions. The Model is able to capture the salience of barriers as well: people can only choose from available options which will influence the type of advocacy they will do.

6 CHAPTER SIX – FUNDING SELF-ADVOCACY

As shown in Chapter 4, practices in self-advocacy go well beyond 'speaking up' and much of what self-advocates and their non-disabled allies do as part of their advocacy is in fact 'para-advocacy' practices ranging from different online actions to seeking support or supporting others and social activities. Analysis of practices also indicated that there may be a hidden hierarchy of practices. Available resources on the one hand, and the skills of self-advocates on the other may strongly influence not only *who does what* in their everyday advocacy but also *who gets to do what*. In other words: who has the resources and potential rewards for doing what they are doing. In fact, it is possible that the availability of resources influences strongly the way self-advocates participate in the disability movement.

In this chapter, the inquiry – keeping with the inductive research approach – turns to the issue of material resources and its importance in the way self-advocacy is positioned in the learning disability and autism advocacy movement.

WHY DOES MONEY MATTER?

As shown in Chapter 2, the issue of material resources has been somewhat scarcely addressed in literature in the context of self-advocacy, even though its importance is acknowledged both in social movement studies (Della Porta & Diani, 2009) and in the context of the broader disability movement (Barnes & Mercer, 2010; Slorach, 2014). Although the funding needs of disability human rights advocacy, for example, the financial needs of DPOs in monitoring rights and evaluating policies and services has been highlighted (Birtha, 2014b), few studies have looked *inside the disability movement* and investigated how available resources are distributed. Existing academic studies have mostly focused on the funding difficulties of self-advocacy groups in neoliberal Britain (Goodley et al., 2014; Runswick-Cole & Goodley, 2015); on the way charities raise funds and potentially maintain disabling and stigmatising discourses (Barnett & Hammond, 1999; McGuire, 2012; Waltz, 2012) or on the financial independence of self-advocacy groups from other organisations or authorities (Bigby, 2015; Buchanan & Walmsley, 2006; Goodley, 2000).

Social movement studies offer a valuable starting point for discussing the relationship between financial resources and self-advocacy. There is a consensus that the availability and distribution of resources in movements impact social movement organisations and their members. Leading social movement researcher della Porta notes that '*in fact, [social*

movement action] repertoires depend on a great extent on the cultural and material resources available to particular groups' (della Porta, 2009 p. 183). This assertion may suggest that the availability of resources to particular groups within the disability movement may affect how these groups and also how other groups with fewer resources operate. For example, it is possible that the three historically separated groups in learning disability and autism advocacy (professionals, parents and self-advocates) have uneven access to resources within the movement – and uneven access to resources may impact how individuals or groups participate in the movement.

Although social movement theory only started to pay attention to the costs of mobilisation from the 1960s and 1970s on, today the costs of social movement activities are considered to be a '*key predictor of individual participation in collective action and social movements'* (Earl & Kimport, 2011, p. 66.). Costs or benefits of participation may affect how individuals join social movements, for example, how much time they devote to participate in an action. Time itself can be costly, for instance when individuals spend time with unpaid protest activities instead of paid work. Social movement theorists also differentiate between pecuniary and nonpecuniary, such as emotional costs, for example when individuals feel anxious about social actions that take an emotional toll on them (Earl & Kimport, 2011). In this chapter, however, attention will be given to pecuniary costs and potential financial benefits of partaking in disability advocacy and self-advocacy, because previous chapters suggested that the availability of material resources may influence the position of members of the disability movement.

The Pathways Model in Chapter 5 showed that self-advocates may take different routes within the contemporary disability movement. Some advocates may join 'traditional', often smaller self-advocacy groups that are likely to be formed by both autistic people and people with learning disabilities. 'Big' organisations such as bigger charities in Britain, national umbrella organisations in Hungary and other DPOs may also be an option for self-advocates, and most of these organisations are controlled by parents or professionals. Finally, a novel form of self-advocacy was also suggested in the Pathways Model, that is the community of autistic self-advocates who work together by various means, including online networks and other collectives – importantly, this type of self-advocacy usually lacks the organisational background of formally established NGOs or DPOs. Members of this autistic advocacy community may often work alone as individual self-advocates while retaining various levels of cooperation with other self-advocates and even other advocates such as professionals

137

and other allies, in a (mostly) virtual community. When looking at the role of financial resources in self-advocacy, all these forms of self-advocacy need to be included in the investigation because it is possible that different forms of self-advocacy involve different financial or other material costs and rewards to self-advocates. In other words: when investigating the role of money, the inquiry must go beyond looking only at organisations.

Following the previously presented open, inductive approach, this chapter will look at the role of financial resources in all possible forms of self-advocacy. Both the financial needs of individual self-advocacy (such as individual income and the costs of practising individual self-advocacy) and the material needs of collective forms of advocacy (organisations, their funding, paid advocacy and self-advocacy positions) will be looked at. Similarly, possible financial rewards will be looked at within individual and collective self-advocacy as well.

Given the lack of previous literature on self-advocacy and its complex relationship with financial resources, the question for this analysis is an exploratory one: **'What is the role of financial resources in how self-advocates participate in different forms of disability advocacy?'**

Of course, in this context, the term 'financial resources' is somehow imprecise. Participants in interviews and focus groups referred to financial resources in various ways, including 'money', 'cash', 'wages', 'funding', 'income', 'costs', 'resources', 'material things' or just 'things' that cost money etc. Financial resources can be present in various forms such as wages, expert fees, reimbursements, benefits, gifts to individuals or funding and running costs of organisations. In the following section, many of these terms will be used and they will refer to any kind of financial resources that are relevant for participants.

6.1 DATA ANALYSIS

To answer the above question, consistently with other sections of this study, an open approach is taken to include the views of not only self-advocates but also parent-advocates and professional advocates. This decision is taken because it can be assumed that the role of financial resources for non-disabled advocates is similar to that of self-advocates'. In other words, if we want to know how money impacts self-advocacy and self-advocates' position in the movement, we need to turn to other forms of learning disability or autism advocacy such as parent-advocacy or professional advocacy to see how parents and professionals appraise the role of funding in their own work.

Based on the Interview Guide (Appendix 5.), each interview and focus group included the discussion of the role of money and financial resources. Although it varied how interviews and focus groups unfolded, participants were generally open to talk about the topic, although some participants preferred not to disclose information on certain issues such as their own personal incomes as advocates. Participants' preferences in this regard were always respected by the researcher. Depending on the researcher's impressions about participants' preferences, the researcher aimed to propose questions in a neutral and polite way, for example by asking '*Do you think money matters in self-advocacy / advocacy? Why?*', however, sometimes questions were more direct, such as '*Why is it impossible to pay self-advocates?*'.

Data analysis was carried out using thematic analysis (Braun & Clarke, 2006). For the analysis, the researcher read all interview and focus group transcripts several times and coded the texts by using NVIVO software. First, two major nodes were created '*financial resources*' and '*self-advocacy as occupation*', which was followed by consequent coding and the identification of emerging themes.

6.2 MONEY IN SELF-ADVOCACY: FROM POVERTY TO PAID ADVOCACY

All participants agreed that 'money' (as a shorthand used by participants for various financial resources) is extremely important in doing advocacy and self-advocacy. There was also a consensus that funding was important for all types of advocacy such as professional advocacy, or the funding of DPOs and charities that support self-advocacy groups, and individual self-advocacy. Not only the funding of advocacy and self-advocacy was mentioned, but also other issues, such as the cost of specific practices advocates and self-advocates do, the income of advocates and self-advocates, and also the overall financial status of individuals and families who may want to access or exercise advocacy. Data analysis found altogether five emerging themes in the context of financial resources and self-advocacy.

6.2.1 Costs of self-advocacy

When asked about the importance of financial resources in self-advocacy, many participants reacted by stating that most practices in self-advocacy, or as they often put it: *self-advocacy itself* costs money. Most commonly two costs were mentioned: the costs of support and the costs of travel. According to a senior British professional advocate, support costs are significant, especially if people try to advocate or lobby beyond the local level – notably, the

139

support includes emotional support as well as support in understanding and partaking in processes.

> *If you require support as most people with intellectual disabilities do, support with understanding the proceedings, support in making the practical arrangements or support to connect A to B, so people need support to keep on track because the anxiety or pressure can become too much so you need personal support, as well as technical support. (…) That's, in fact, the most expensive aspect of it, paying for the support.* (British advocate in learning disability*)*

A professional advocate in Britain agreed with the previous statement, adding that although voluntary support may be available but it cannot fully substitute paid support, even if financial resources are limited.

> *They [self-advocates] may need guidance to… to get the right ears to listen and there's nothing out there because there is such a lack of funding and volunteers can only go so far.* (UK professional advocate in learning disability)

Support needs and costs of support may be similarly significant in autistic self-advocacy. According to a Hungarian parent-advocate in autism, self-advocacy is a '*very expensive'* thing, especially when support requires technical knowledge of special tools in communication. Here, support with specialist communication expertise is seen as pivotal as sign language interpretation for deaf people, suggesting that such support is far from optional, on the contrary, it may be fundamental in enabling self-advocates:

> *I do think that the tools by which we can boost their [self-advocates'] collective advocacy, well, these are VERY expensive. (…) for example when you want them [self-advocates] to gain experience and be able to use visual communication materials so they can advocate for themselves. (…) It's like training a sign language interpreter, to help them in communication or in understanding things. And this costs money.* (Hungarian parent advocate in autism)

One self-advocate with a learning disability stated that costs go beyond support, and they include paying for the venue and the costs of reaching out to potential new self-advocates.

> *Researcher: Do you think you need money to run [self-advocacy] groups?*
> *Self-advocate: Well, if you have support then you need to pay for it. (…) You need to look at the different issues: you need support workers, you need the venue, you need*

to write grants and to find people who are interested… (Hungarian self-advocate with a learning disability)

A British self-advocate gave a very similar statement and pointed out that costs of support staff, venues and organising events such as accessible meetings for self-advocates all cost money which is necessary for doing self-advocacy.

Researcher: What do you need money for?

Self-advocate: Going to speak up at places like universities and lobbying universities and lobbying MPs, to get about you need money to buy and to pay for transport and also for someone to take part in leisure facilities and also make their organisation very… for example when people come to visit a self-advocacy organisation, they need to make it very relaxing and welcoming because that's what advocacy wants to do but also the most important is that like with everything about learning disability, you need a budget to employ staff. (British self-advocate with a learning disability)

Transport costs were mentioned by other participants as well, usually, because members of collective advocacy initiatives need to be able to get to meetings. A professional advocate living in a rural area saw travel costs as potential barriers to those who have financial limitations.

I am thinking about the autism groups we have here and in terms of money and the fact that they do travel quite a lot and that can be potentially very difficult for someone who didn't have very much money so it [money] does [matter] I suppose, if you can't get the bus to that meeting. (British advocate for autistic people)

An important similarity between members of the movement is that many parents find financial issues similarly hindering when they are trying to access or exercise advocacy. For example, families of disabled children may find travel costs difficult to cover. According to a Hungarian advocate, lack of money often hinders families from accessing legal aid:

Only those families come to my legal aid service who can afford to get into their car and drive up to Budapest because I cannot travel to the country to see them. (Hungarian professional advocate in learning disability)

The costs of transport were usually mentioned by participants whose experience included working with individuals or families living in rural areas. For example, a British advocate

141

stated that the lack of affordable transport network in her region seriously hinders people of lower income to get to meet peers and practice collective advocacy.

> *It's [money] hugely important. Just to be able to go places in order to organise, you know, if you have to travel to somehwere and if you live in Northern Ireland, there is no transport at night, so if you want to go to meetings you have to take a taxi or else you have to be able to drive. So if you can't drive or you can't afford a car, then you are limited unless you take a taxi to go to places. And that's very expensive, so that's a limitation on people to organise and to get together.* (British professional advocate in learning disability)

Advocacy may involve other costs too, for example, fees for a specialist, such as legal expertise. As shown earlier, strategic litigation is one of the possible and potentially impactful ways disabled people can challenge the status quo (Flynn, 2013). However, litagation may be costly which hinders people from taking legal action to advocate for themselves or their families. A professional advocate stated:

> *There are so many barriers to doing strategic litigation for people with an intellectual disability. Starting with that the majority of people are not earning, and are living on welfare to some extent. In the UK access to funds to pay for litigation have been cut so it is more difficult for people to take legal action than it would have been. (British professional advocate in learning disability)*

To conclude, the theme 'costs of advocacy' may include several factors that are possible barriers to potential self-advocates. Not having substantial funds to hire support staff may impede collective forms of self-advocacy. Equally, in the absence of organisations with appropriate funding, lack of access to support staff may hinder self-advocates who wish to speak up. Transport costs may exclude those living in low-income households and those in areas with under-developed and/or expensive transport, especially in rural areas.

This means that a potential 'entry point' to practising self-advocacy, which is meeting peers, attending events and joining group activities may be impossible for many autistic people or people with a learning disability on low income or for those living outside metropolitan areas. Consequently, those who could potentially be involved in the self-advocacy movement may be unable to do so simply because they do not have enough money to get to meetings or there is no staff who would support them to learn and practice self-advocacy. This finding points at the next theme which is participants' views about those members of

142

the disability movement who can eventually practice advocacy and self-advocacy: people *'who can afford it'*.

6.2.2 'Those who can afford it'

This theme concerns the income of those working in jobs that include advocacy or others who practice advocacy and self-advocacy. The theme is called *'those who can afford it'* because several participants stated that advocacy for them was actually a career choice that ran against their financial interests, with one Hungarian parent-advocate stating '*doing advocacy is a luxury'*. Although the theme seems relevant for all people who do advocacy or self-advocacy, it emerged predominantly from parents' statements. For example, a parent-advocate and senior member of a known advocacy organisation stated that jobs offered at NGOs and DPOs[20] only offer modest income.

> *You will never earn the same amount at an NGO as you would at a multinational company, even if you work five times as hard. So only those people can work here "who can afford" to work here, and this means people who have a certain background. A background which is surely not poverty. (…) I am not saying that if you live in poverty you cannot stand up for your rights, but I do think that… this will sound stupid but I think doing advocacy is a kind of luxury.* (Hungarian parent-advocate in autism)

The opportunity to do advocacy as a job may be influenced by not only the financial situation of a person but also by their specific needs. In a focus group discussion in Hungary, experienced parent-advocates who were also involved in organisations, compared these individual needs to the 'hierarchy of needs' scheme developed by Maslow. The 'hierarchy of needs' is a five-tier model of human needs, ranging from fundamental needs such as physiological and safety needs through belongingness and self-esteem needs to the highest tier which is self-actualisation, for example, the need to feel accomplished (Maslow, 1943). Maslow's theory is a well-known, and much-debated one in popular psychology (McLeod, 2007) – here, participants employed 'Maslow's pyramid' to explain why many people choose to focus on fulfilling their more fundamental needs instead of doing advocacy.

> *Advocate 1: Yes, it [money] is absolutely necessary, and I think Maslow's pyramid is very relevant here. People want to feel safe first. Yes, people need money, because when I really struggle to make ends meet then I can't just run to start to join advocacy and do this here [at her organisation], until my own and my family's financial safety is*

---

[20] In Hungary DPOs are usually seen as a subcategory of NGOs (Hegedűs et al., 2009).

not ensured! So only after it is [ensured] can I go and fight for others. It [advocacy] will

always be secondary.

Advocate 2: Yes, I agree with this, it is much, much harder when the family's [financial]

situation is so difficult that none of the parents has advocacy on their mind.

(Hungarian advocates in learning disability)

Parents also mentioned how advocating for their children may mean that they are working extra hours, often in evenings which may easily lead to burnout prompting them to leave advocacy. This signals how the lack of financial resources may impact long-term commitments in advocacy. Parents, and possibly other advocates sometimes need to give up spending time with advocacy, because they need to work to support their families, or because they need to look after their – disabled and non-disabled – children. One parent-advocate who had been leading a parents' organisation for many years emphasised how challenging it was to prioritise between advocacy and family life.

This is VERY DIFFICULT. [with emphasis] I've been working with families for many years

now, and I see these parents… when you work to make a living during the day, you

work for your family, and then at night you have to sit down and carry on and work on

things relating to advocacy, then this can quickly lead to burnout. They can get

absolutely burned-out, especially if they do this for many years. (Hungarian parent-

advocate in autism)

Financial rewards for parent-advocacy are usually minimal. A British parent-advocate said her advocacy '*does generate some [income], not much, very, very little*', even though she has been practising parent-advocacy such as speaking at conferences and giving trainings for many years.

Low salaries in advocacy were also mentioned by professionals, for example, a professional advocate – who is also a parent of an autistic child – simply stated '*you cannot make a living as an advocate*'. Her view is supported by a British advocate who said she was taking on a second job in order to be able to work as an advocate, the occupation she is committed to do.

It's a quite varied work and I love doing it which is why I am looking for other things

for supplement income so I can stay doing it. (British professional advocate in autism)

Some participants asserted that innovative initiatives in advocacy, or establishing new advocacy organisations are linked to the financial backgrounds of people who may take such initiatives. The following statement by the leader of a Hungarian advocacy organisation suggests that starting new initiatives may only be possible for 'those who can afford it'.

> *If you think about all those people who started new NGOs or initiated new things in advocacy, then think about who they are. They all needed a certain financial background, to be independent. It is not enough to have the right attitude. Think about the background of those in leading roles! (…) All of them are of higher social status, upper middle-class, not even just middle class but above. [names eight different organisations and their leaders] All those I know are people like this.* (Hungarian advocate in learning disability)

As seen earlier, advocates and self-advocates share not only most practices they do, but they also share many problems they face. Thus, it is not surprising that parent-advocates' views on their own advocacy are similar to how they see self-advocates' 'needs of hierarchy'. One Hungarian parent-advocate stated:

> *By the way, I think the same about self-advocacy, if someone is struggling to get just above the poverty line, that person will obviously have no chance to even advocate for his needs outside that.* (Hungarian advocate for autistic people)

This statement was reiterated by an autistic self-advocate in Hungary who said '*when your days are overwhelmed by things you must do, and when you need to earn a living beside [doing advocacy]… then we are behind the eight ball again*.' Here, income was contextualised, once again within the 'hierarchy of needs' for self-advocates. In the statement of a British autistic self-advocate, class-divisions are mentioned along Maslow's theory, and the context includes not only access to advocacy but also how people can access an autism diagnosis.

> *I think there's definitely middle-class and upper class, and it's having the time, the hierarchy of needs, having the time to be able to [advocate]…, you know. (…) I think doctors probably didn't even diagnose different people from different cultures or from different classes or parents didn't have the time or the energy to deal with the different situations the same way an upper-class family would.* (UK autistic self-advocate)

The theme '*those who can afford it*' implies that many people with a lower income are in fact often 'locked out' of advocacy or self-advocacy. Many potential advocates and self-advocates have little time to devote to advocacy because they are focusing on their more fundamental needs to 'make ends meet'. Maslow's hierarchy of needs was referred to by various participants from Hungarian parent-advocates to British self-advocates signalling an overarching relevance to this theme in the advocacy movement.

This theme can also be applied to the Pathways Model presented in Chapter 5. When people start doing advocacy or self-advocacy, they may be facing a choice: they can accept that advocacy generates modest salaries, and carry on doing it, or they can choose to turn away from advocacy and just 'work for their families' or themselves. Based on data presented above, the reality of present-day learning disability and autism advocacy is that only those people are most likely to engage with advocacy on a longer term who can supplement their salaries from other sources or those who have the financial background due to their social status. Thus, this may mean that most people engaging in long-term and more formalised advocacy such as advocacy organisations may come from better financial background. People with lower income may be less likely to be found in advocacy because they 'cannot afford it'. Notably, participants did not claim that people of lower income cannot do advocacy at all. Instead, they emphasised that it may be very difficult but it is a personal choice to engage with advocacy despite one's limiting financial background.

6.2.3 Poverty – those who *cannot* afford it

Although the thematic analysis was looking at emerging themes in the context of self-advocacy and advocacy and financial resources, one salient theme that emerged is 'poverty', which seems to be a broader societal issue rather than specific to advocacy. Poverty was found to be closely related to the previous theme 'those who can afford it'. This theme draws attention to those potential advocates and self-advocates who may be interested in joining the disability movement or DPOs, but who live in low-income households – *those who cannot afford* to do (self-)advocacy. In other words, one of the core issues in the context of advocacy and money is poverty, the daily experience of many disabled people and their families around Europe (Inclusion Europe & Inclusion International, 2005).

The view of one parent-advocate who has several years of experience working with families around the country seems dark but it points at an important issue that may explain why some people do not join disability advocacy.

146

> *When you are struggling to even put porridge in front of your child then you have no time to think about the lack of special needs assistance in his school. You may not even care that your child is autistic.* (Hungarian advocate in autism)

A member of a Hungarian self-advocacy group sums up her experience of poverty by explaining how even daily hygiene can be an issue for those living in low-income households.

> *I get help now, the Maltese[21] or the Red Cross come and they bring clothes to wear. This is important. The clothes and that you wash every day. And that you look good, you wear proper clothes. When I can't then they tell me to take a shower which I can do at their place. This helps me a lot.* (Hungarian self-advocate with a learning disability)

The daily reality of poverty was pointed out by British participants as well. One professional advocate in South East England stated that many people do not access advocacy because they are unemployed and get very little help from authorities even to leave their homes.

> *People who are extremely vulnerable, but whose IQ isn't below 70 they are not getting any services or any support and they are actually really struggling to survive you know, they are not leaving their house, they can't get an employment because they haven't got the support to be able to have a look and find an employment, and all the government say is you have to attend this workshop and they are unable to leave the house and unable to get to the workshops and they get penalised for that.* (British professional advocate in autism)

One of the main reasons for poverty is the lack of employment opportunities. Several autistic participants stated that although they were committed to find a job, but they were unable to take on full-time jobs, which impacted their income adversely. An autistic self-advocate expressed her frustration because although she saw employment necessary 'to make a living', due to her condition she was unable to join full-time jobs.

> *I, for instance, do not want to depend on social welfare, the disability pension and all that. But I do not, I cannot work eight hours a day all the time which is what you have to do to make a living.* (Hungarian autistic self-advocate)

---

[21] The Order of Malta – referred to as 'Maltese' [in Hungarian '*Máltai*'] by the participant – runs a well-known charity in Hungary that offers various social services including shelters and food banks.

147

The relationship between living on welfare benefits and poverty was explained by another participant, who stated that the socio-economic system effectively excludes disabled people who cannot work.

> *Their intellectual impairment may be a reason for their financial exclusion, because they are not in employment, and they are paid less, and the benefit means less money so they can't afford it. So, the exclusion is a socio-economic one, because of their impairment*. (British advocate in learning disability)

Related to poverty and also to one of the previous themes – the costs of self-advocacy such as transport costs –, the views of a British advocate at a national charity draw attention to broader social issues.

> *Transport isn't an issue for people with a learning disability, it's an issue with no money, and it's really important we don't overlay social problems and just say this is a problem for people with learning disabilities. The reality is if you live in a rural part of Wales and you don't have access to a vehicle transport it's gonna be a problem for you. But that's because you have no money or enough resources to either purchase a car or pay for taxis because buses are very, very rare.* (British advocate in learning disability)

Transport, however, is not the only cost that people living in poverty find difficult to pay for. In the following example, Hungarian advocates discuss how poverty and access to advocacy may intersect. The example of a pro bono legal aid service for disabled people in Hungary reveals that some people may even find it difficult to access free of charge advocacy services.

> *Researcher: Do you think poverty influences who can come to your [advocacy] meetings?*
> *Advocate 1: Yes, I think those living in the countryside are very much disadvantaged...*
> *Advocate 2: Yeah. I remember once someone told me on the phone 'Thank you for helping us through the legal battle, but do you know if I can get a refund for the costs of the phone calls I made when we talked?' And I almost got a heart attack, I thought how rude they're because I did the whole legal work for them pro bono... On the other hand, making phone calls may be a significant expense for them! We make a huge mistake when we assume that it is a gift that they can come and tell their problems. In fact, even making phone calls may be expensive for them*. (Hungarian advocates in learning disability)

Poverty is a result of low household income, which is a major barrier for those wishing to speak up and advocate for themselves, for their peers or for their families. Many autistic people and people with a learning disability live on welfare benefits because employment levels for disabled people are low in both countries (ANED, 2018). Poverty has been an everyday experience for people with a learning disability in both countries, and across Europe (Inclusion Europe & Inclusion International, 2005). Dropping welfare benefits and social support has severely impacted disabled people in many European states since the financial crisis (Hauben et al., 2012). Poverty is not only one of the most regular forms of social exclusion that impacts disabled people and their families but is also one of the main barriers why people, including parents and potential self-advocates, cannot access even the simplest forms of advocacy. The 'hierarchy of needs' referred to by several participants in both countries may be a useful tool to predicting whether individuals may be able to join certain types of advocacy.

6.2.4 Self-advocates' independent income

One salient theme was the independent income of self-advocates. Although this theme is closely related to one of the previous themes 'those who can afford it', but it stands separately here, for two reasons. First, the present study puts self-advocacy in its focus and enquires about the factors that help or hinder self-advocacy in the disabled people's movement. Thus, discussing the salience of personal income in self-advocacy separately is central even if income is important for all advocates. Second, based on participants' views, the role of income in self-advocacy is different in many aspects from the way income was framed in parent-advocacy or professional advocacy. For example, some self-advocate participants such as one autistic self-advocate saw financial independence as a necessary prerequisite to successful advocacy.

> *I think the capacity and the [financial] stability of autistic people need to be ensured to enable them to work in advocacy. This can be done in different ways, from top to bottom, for example when someone gives money or nurtures[22] them. But I have bad experiences with help from the top. I do not trust the state, and I personally think that autistic people need to become their own advocates. So, they must get closer to*

---

[22] The Hungarian verb in the original interview is '*kinevelni*' which may mean both 'educating' and 'nurturing' someone.

149

employed positions [in the movement]. As a first step, they need to take care of their own safety and material well-being. (Hungarian autistic self-advocate)

According to another participant, the lack of financial independence may lead some self-advocates to 'selling' their opinion.

You can also see those who sell their opinion, just to be able to be among others. We need to tackle this, these are biased positions, and it is not good if autistic opinions are distorted like this. You need [financial] stability. (Hungarian autistic self-advocate)

Some self-advocates with a learning disability felt that their financial background was strongly related to their social status, for instance how they can present themselves in public or how people see them. In the statement of a participant with a learning disability, financial well-being meant being able to wear socially approved clothes, being able to go to meetings or being able to have enough money to invite peers for a drink. This highlights that self-advocates with a learning disability recognise that social status is something they need to achieve, and financial well-being (income) may be one of the ways to social acceptance.

Researcher: Do you think people need money to do self-advocacy?
Self-advocate: Yes, on some level, yes, because there are social problems and people need to wear proper clothes, they need to wash. If they get financial support, they can become good self-advocates. They can understand more, they can go to the library and go to meet others, and they don't have to feel embarrassed because they smell bad. And they can also invite friends for a drink so they can talk, share experiences and establish contacts. (Hungarian self-advocate with a learning disability)

Independence may also be facilitated by financial means, for example when a person has their own income. A British self-advocate with a learning disability told her own story when she started to get a salary for her advocacy position at an organisation. For her, earning a salary instead of relying on welfare benefits was also related to becoming independent and moving out from a residential social service.

But then I got a wage. That's why they [social services] don't like XXX organisation very much because XXX organisation sort of let the reins off me (…). I said to him [manager of social service] I don't care anymore, I just gonna work that's it. I moved out. I've got a husband, I've got a child now, live on our own, XXX organisation still give me that support to access to work. (British self-advocate with a learning disability)

The relationship between paid work and independence was further explained by a British professional advocate who recalled the example of a self-advocate with a learning disability who got into a paid position at their organisation.

> *These are basic things that give you a sense of strength. And one dimension of that is a status as an employee. Her status as an employee. She's paid, and this gives her a sense of dignity, stature, being valued alongside other people in our world, so she's paid, and she's paid not minimum wage (…) So their awareness of what others are paid and fairness, status, position so for her that's as significant as for anybody else.*
> (British advocate in learning disability)

However, paid positions for people with learning disabilities were seen exceptional. Other participants saw the lack of employment a major social problem that hinders most disabled people from being independent. In the words of a British self-advocate with a learning disability, getting a wage as a self-advocate at a charity is a career that should be available to more of his peers.

> *I got a great career at XXX charity and I would like to build my career here and I believe people with a learning disability can actually hold high profile jobs and I think the sad thing is that in this country not many people with a learning disability have jobs at all, and sadly only 7% of people with a learning disability are in paid work. I think that is really, really bad. (British self-advocate with a learning disability)*

In the absence of available jobs, some self-advocates try novel ways, for example, they start their own businesses as consultants or do self-advocacy alongside another job. One British self-advocate saw this as a possible, but very difficult way of engaging with advocacy.

> *Earning money…? Some people don't disclose to their employers that they do it [self-advocacy] as a side thing, and it also gets more complicated because the tax... if you have a second job the paperwork gets overwhelming. (…) Its logistics, being self-employed is stressful, to be sure that they will pay you, like for instance when I worked at the XY, they just paid me for the hours but obviously if you do it all on your own then you have the paperwork on your own and if you haven't got the support it can be quite overwhelming and you just don't know where to start.*
> (British autistic self-advocate)

Lack of income and more specifically, the lack of independent income is a strong barrier for self-advocates. For people with a learning disability earning a salary is often seen as part of a 'greater package' that is independence from social services or it is part of gaining a higher social status – things that are all closely related to their basic aims when people start doing self-advocacy (as shown in Chapter 4 and Chapter 5): to be part of a community, to be supported and to support, and to be able to speak up about issues they feel important. For autistic self-advocates, having an independent income as advocates was also related to freedom from influence and bias, for example, influence by the state or by those wishing to sponsor them. All participants agreed that it is crucial that self-advocates speak up for themselves and income enables them to do so. Some opinions suggested that self-advocates may try to do self-advocacy as independent or freelance ('self-employed') consultants. However, in the context of jobs outside advocacy organisations, bureaucratic burdens and financial instability were mentioned.

The lack of available employment in the labour market may be one of the main barriers why self-advocates cannot be financially independent – this is a barrier *outside the disability movement* that strongly effects self-advocates' participation in advocacy. However, income could also be earned *within the disability movement*, as employees of organisations. This leads to the next salient theme: self-advocacy itself, similarly to other types of advocacy rarely involves a paid job.

6.2.5 Self-advocacy is unpaid

When participants were asked about their thoughts on self-advocacy as a paid job, some participants' first responses were emotional in a dismissive way, suggesting 'there is nothing to talk about here' – reactions expressed through body language and words implied as if the question itself was somehow inappropriate or even silly. On the other hand, actual interview transcripts provided rich data on how participants viewed self-advocacy as a potential source of income. This contradiction between first emotional responses and actual views expressed in words is very telling, and can be explained by looking at the theme '*self-advocacy is unpaid*'. Although all professional advocates and most parent-advocates got various levels of remuneration for their advocacy work, this was not the case for most self-advocates.

The views of a Hungarian advocate in autism sums up the experience of many self-advocates both in Hungary and in the UK; although self-advocates rely on their income just like everyone else, they are rarely paid, in fact, self-advocacy is seldom recognised as 'work'.

152

I do not know anyone who is a paid self-advocate. (…) If they are not paid for it, if there is no money to pay them, if that is not seen as work then it becomes extremely difficult, because even a self-advocate needs money to buy milk. (Hungarian advocate in autism)

Many self-advocates stated they did not get paid for their work the same way other advocates did, mostly because they were not in advocacy jobs, or organisations simply did not pay them when they were involved in projects. For example, one autistic self-advocate in Britain recalled one event where a leading autistic advocate did not get remunerated for his work, even though he took an active part in the preparation of a programme.

So XY [names autistic self-advocate] *is like… organising the whole seminar, a conference, on research in autism, and they can co-organise with these autistic people, but the only difference is he doesn't fucking get paid!* [raises voice] *They get paid and he doesn't get paid!* (British autistic self-advocate)

Of course, self-advocacy (as seen in Chapter 4) may cover a very broad variety of practices, including practices outside the strictly understood 'speaking up'. It can be assumed that people do not expect payment for practices such as being online to chat with peers, for learning, or for contacting other advocates. When self-advocates recalled what they do in the context of paid v. unpaid advocacy, they often saw self-advocacy as a necessary and needed practice, even if not paid.

If I had done everything that I'd done on the idea that ideally this is what I want to be paid and this is my travel [expense], then I wouldn't get much done. (…) And I end up supporting other people and other people support me in that kind of underground movement, more than being supported by the council. I think you have to have the drive to do it and I think that's the most important thing. (UK autistic self-advocate)

In both countries, several autistic participants stated that they do self-advocacy despite the fact that they do not get paid for it. One Hungarian autistic self-advocate stated he was deeply committed to self-advocacy: '*Yes, this is voluntary work, but it has this element of… love. I love doing it*.' At the same time, when asked about the financial needs of self-advocacy, all self-advocate participants in both countries agreed that self-advocacy – similarly to advocacy, as seen above – requires financial resources for travel, for support workers or for other costs such as equipment. For example, one autistic self-advocate

estimated that around one million Hungarian forints (approx. 2600 GBP) had been spent on audio and video equipment that they used for running their video blog on autism.

When asked whether self-advocates saw their work as a potential source of income, several participants responded similarly to the following view. The below statement is by an autistic participant who had been giving lectures for several years.

> *Researcher: Can self-advocates make a living out of advocacy?*
> *Self-advocate: No, they can't, not yet. Right now, here in Hungary, in 2016, they can't. Maybe this will change sometime, but this is the reality now.* (Hungarian autistic self-advocate)

Although self-advocacy means usually unpaid work, but sometimes it does generate some income, in the words of a self-advocate, a '*funny amount*'. For example, the previously quoted autistic self-advocate in Hungary added that

> *…we do have a little income, so it is not true that it is absolutely pro bono work, because we have a minimal income. We found this opportunity, an online crowd-funding site where people can support our work. What we get through this is a 'funny amount'.* [smiles] *But it already helps us a great deal[23].* (Hungarian autistic self-advocate)

The lack of payment for self-advocacy, however, was not accepted by all self-advocates, for example, one self-advocate with a learning disability said it was unacceptable for her to work pro bono if others get paid for the same job.

> *Researcher: In Hungary, people are not always paid for self-advocacy. Is it different here?*
> *Self-advocate: Yeah, they do it there for love? I think we need to get paid because I'm being on for years and if you want me… I am not doing it for charity! I need to get paid 'cause I got bills to pay and other things to pay so can't do it for nothing and when I work for NHS, people get paid too for the training, so why can't we get paid to do the training, cause we do the same thing, same place so we should get paid. (…) Cause people get paid vouchers and that's not really getting paid work it's just charity really.*

---

[23] In October 2018 the crowd-funding site generated 41 USD per month.

> *Ten pounds vouchers and sometimes you don't get paid at all! So yeah, people need to get paid for the work.* (British self-advocate with a learning disability)

Showing that there was no consensus among self-advocates about their stance on paid advocacy, one participant recalled that many self-advocates do work pro bono, despite other autistic people's disagreeing with this.

> *There are quite a few autistic speakers who would speak for free and that really hacks me off because I can't afford to do that*. (British autistic self-advocate)

In the context of collective advocacy, the difference between paid and unpaid advocates was seen controversial by not only self-advocates but professional advocates as well.

> *The 'young adults group', their job is specifically to self-advocate on their group's behalf to the council, and I don't think they are paid, again... I think when people are doing a job that other people are getting paid for then, for example, council workers get paid, so they should be paid to some extent.* (UK advocate for autistic people)

On the other hand, some participants disagreed and stated self-advocacy was not work and should not be viewed in the same way as other roles in the advocacy movement. The view of a senior advocate at a known charity draws attention to divisions within the movement (and possibly divisions within organisations) in how they see self-advocates' work.

> *It* [learning disability self-advocacy] *is not work so I think it's dangerous to tell people they are doing work. It is volunteering. What you have in all organisations between paid staff and volunteers, in Oxfam or in Stonewall, so you have paid staff members and you also have self-advocates or people with a particular interest in trying to change society.* (British advocate in learning disability)

Here, the difference between paid and unpaid self-advocacy may be influenced by the form of advocacy people choose to work in. For example, a British autistic self-advocate does not accept money for her work, but she recognises the importance of some level of reimbursement for the costs of self-advocacy such as transport. The following opinion brings attention to personal choice: while some people decide to do pro bono work, others may have no such option, because they are not even offered remuneration.

> *I personally don't accept money for what I do, because actually... it doesn't fit with me. But if you look at other things, like booking a room or to buy petrol or things like that obviously you're gonna be talking about a lot of money that sometimes need to*

155

be covered. So, I can understand that bit. It just seems strange to me that you need to
go and talk or [you need to] make money. (British autistic self-advocate)

Indeed, the decision to pay (or not pay) self-advocates may also be made by organisations who control resources: for example, NGOs and DPOs employ staff and decide about levels of salaries employees get. When asked about paid self-advocacy positions in organisations, a group of senior leaders of advocacy organisations (all parents of autistic people) raised several questions.

> *Researcher: Do you think advocacy organisations could employ paid self-advocates in Hungary?*
>
> *Advocate 1: I don't think so, this is not possible right now. Who knows, maybe in the future…*
>
> *Advocate 2 & 3 & 4 [speaking over each other]: I do think so. Yes. This could happen.*
>
> *Researcher (to Advocate 1): Why do you think it's not possible?*
>
> *Advocate 1: You asked if someone could work in an organisation as a paid [autistic] self-advocate and I know many organisations and based on what I know, I don't think they are ready. They don't have the capacity, I mean they don't have the time and the money. If you hire someone to self-advocate then you need to support him, to provide him with competencies he needs, and all this cost a lot of money. I don't think I know one single organisation in this country that could afford this so I think no, it is not realistic to employ paid self-advocates in the near future.*
>
> (Hungarian advocates for autistic people)

The above debate calls attention to organisations' inner practices and their allocation of resources, for example, what opportunities they offer to self-advocates and whether paid positions are available for autistic people or people with a learning disability at NGOs. In Hungary, only one organisation employed one self-advocate with a learning disability on a regular basis, and only 'freelance' autistic self-advocates, working outside DPOs and NGOs got some remuneration for their advocacy work. In the UK, two participants with a learning disability got a regular salary for their work as self-advocates, and one was employed by a charity as an office helper whose job also involved participating in self-advocacy projects.

Self-advocacy is rarely remunerated on the same level as other types of advocacy. DPOs and NGOs seem to be maintaining structures where self-advocates are rarely paid on the same level as non-disabled advocates. In fact, findings indicate that self-advocates may often be a

source of unpaid labour at organisations. It is possible that the level of remuneration is also influenced by the form of self-advocacy one does. It can be assumed that collective and individual forms of self-advocacy may offer different options in terms of how much income self-advocacy can generate.

6.3 CONCLUSIONS – FUNDING AND INCOME AS BARRIERS

Five themes emerged from the accounts of advocates and self-advocates in the context of funding. The availability of financial resources was found to be a major factor that influences how self-advocates participate in the disability movement.

Doing self-advocacy – especially more formal, organised or long-term self-advocacy – requires financial resources. Running self-advocacy groups involves costs for organisations. Among the costs of self-advocacy, mostly the salaries of support staff, transport costs, costs of venues and organising meetings were mentioned. Lack of paid support staff may be one of the most important barriers for self-advocates because they need support to attend meetings or to follow complex proceedings advocacy engages with. Transport costs may seriously hinder those living in rural areas.

Poverty is a common experience within the learning disability and autism community. Those families and disabled people who live in poverty may not have the opportunity to devote time to advocacy or even to access free of charge advocacy services. It can be assumed that self-advocates from low-income backgrounds find it much harder to join collective forms of self-advocacy or even to exercise self-advocacy on their own. The 'hierarchy of needs' model by Maslow (Maslow, 1943) seems to be a relevant 'rule of thumb' in explaining why people with low income may not be able to engage with advocacy and self-advocacy.

The relationship between funding and self-advocacy is a complex one. For example, organisations and extra-organisational self-advocacy may offer different rewards and costs for individuals. Some self-advocates – similarly to some parents – follow individual pathways and try to generate income from 'freelance' types of (self-)advocacy. Although most participants stated self-advocacy is in fact work and should be paid, this view was not shared by all non-disabled advocates and even some self-advocates continue to work pro bono.

Findings show that the disability movement may be running systematic barriers that maintain the exclusion of self-advocates from paid positions in the movement. People with a learning disability and autistic people face a low level of employment across Europe including in the UK and in Hungary (ANED, 2018) partly due to lack of employment

157

opportunities provided through forms of reasonable adaptations at workplaces (Moody et al., 2017). Based on findings, it seems autistic people and people with a learning disability do not get much better opportunities to work in salaried jobs in the disability movement than they get outside the movement. This results in a situation where self-advocates are seen more like passive recipients of advocacy services even if they actively contribute to projects, initiatives, and the running of collectives or organisations. This proposes a serious question that concerns the very values the disability movement claims to be built upon – if inequality and social exclusion is maintained by economic means *within the movement* and *by the movement* then the disability movement including DPOs and other organisations may be violating the very rights they are supposed to be fighting against.

PAID ADVOCACY

'FUNNY AMOUNT'

UNPAID

Paid, extra-organisational self-advocacy?

Organisations

Unpaid self-advocacy work

'Those who can afford it'

P O V E R T Y
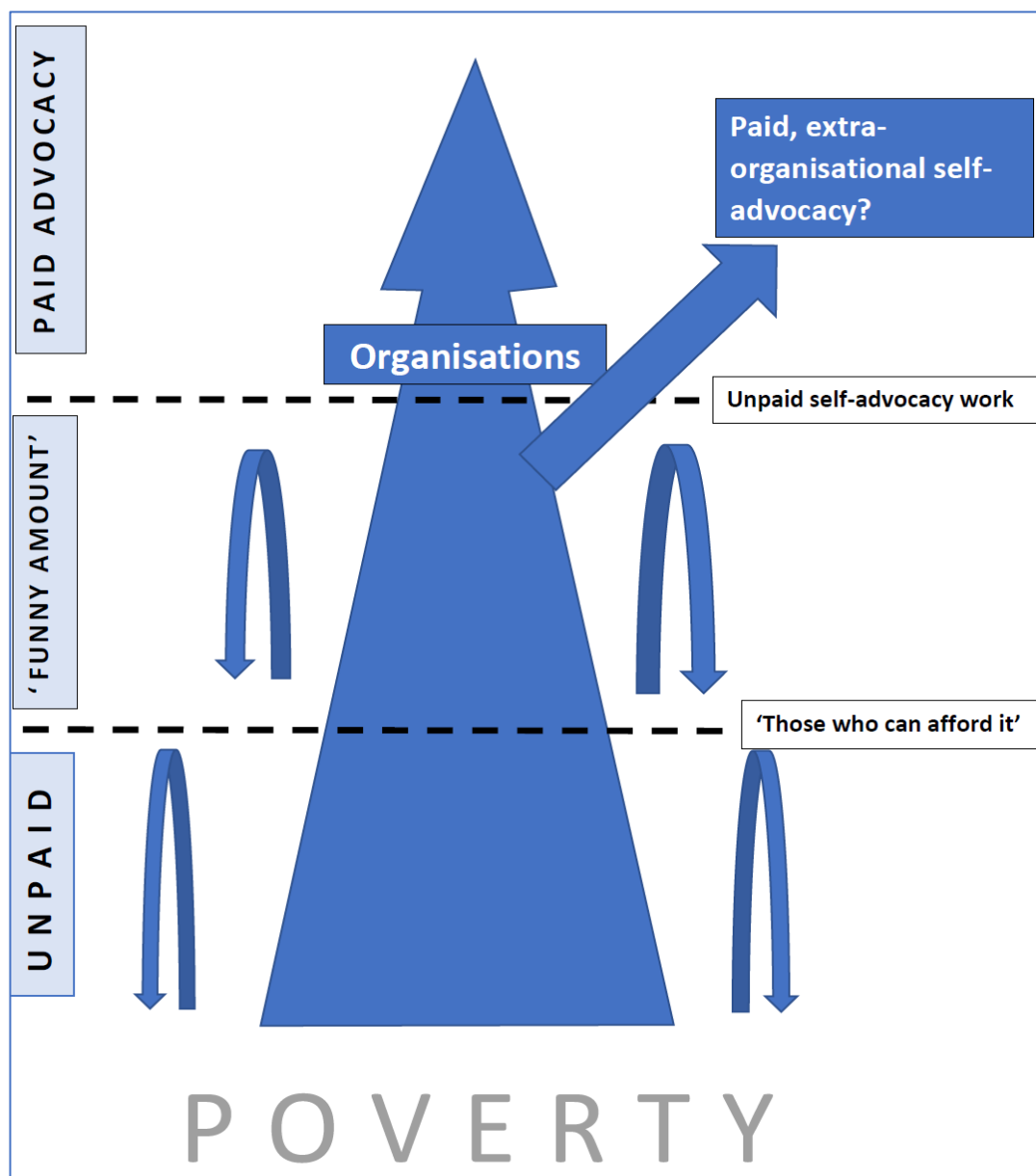
Figure 6.1 Pathways and barriers to funding self-advocacy

The findings can also be integrated with the Pathways Model (Chapter 5) which, as a heuristic device aids our understanding of how the availability of funding can impact self-advocates' position in the movement. The above model (Figure 6.1) represents how different themes found in the analysis may also act as barriers that impact self-advocates' participation in the disability movement.

The figure shows that pathways to self-advocacy can be substantially altered by lack of resources. Lack of funding (such as lack of paid labour or low salaries) may turn many self-advocates and other advocates, including parents and professional advocates away from working in the movement. Based on participants' views, paid positions offer low rewards for advocacy, making advocacy jobs less attractive compared to other jobs. The theme 'those who can afford it' seems emblematic in explaining that many members of the learning disability and autism advocacy movement may take part in the movement because their personal background allows them to do so – supplementary incomes or middle-class and upper-middle-class background were mentioned as enabling factors in predicting who can stay in long-term advocacy positions. Importantly, the barriers in the figure ('those who can afford it' and 'unpaid self-advocacy work') are not solid lines, signalling that people can still 'slip through' and decide to stay in the movement and work as advocates, against their financial interests. However, findings suggest that such choice may not always be possible for self-advocates who often live on welfare benefits making them more dependent on others such as their parents or social services. Low levels of employment also seriously hinder autistic people and people with a learning disability to be able to practice self-advocacy.

On the upper level of Figure 6.1, two main types of self-advocacy are seen, because self-advocates in organisations and outside organisations face different opportunities. While organisations do control certain level of funding, and can allocate salaries to self-advocates, individual (self-)advocates need to look for funding themselves. This was seen to be difficult but possible. Indeed, several participants had some experience in fund-raising for their individual (self-)advocacy. '*Paid, extra-organisational self-advocacy*' is marked with a question mark in the figure, because participants stated positions that generate income outside organisations were present but rare. Findings indicate autistic people and people with a learning disability have only very limited opportunities to work as self-employed or freelance (self-)advocates.

To conclude, several factors were found that may impede self-advocacy. It is possible that members of the following groups have a much lower participation in self-advocacy, or their self-advocacy is hindered because of financial reasons:

- ➢ People living in rural areas or in areas with only expensive transport options.
- ➢ People living in poverty or in low-income households.
- ➢ People living solely on welfare benefits.
- ➢ People not earning enough to be independent financially from others.
- ➢ People whose working hours in employment do not allow them to engage with self-advocacy.

It is possible that the differences between organisational and extra-organisational self-advocacy go well-beyond the context of funding, and individuals may recognise other rewards behind both of these options. In the following chapter, individual and collective types of self-advocacy will be compared.

7 Chapter Seven – Organisations and self-advocacy

The previous chapter demonstrated that the position of self-advocates in the disability movement is strongly influenced by factors such as the availability and distribution of resources. The level of income one has, and the remuneration for the work self-advocates do fundamentally impact how people join and participate in the movement. Furthermore, available resources are often redistributed by organisations. It was also presented that self-advocates sometimes work outside disability organisations, for example as 'solo' self-advocates when they establish themselves as volunteers, experts, consultants or entrepreneurs – formal organisations seem to be covering most but not all parts of the disability movement.

The Pathways Model, presented in Chapter 4 also presented that self-advocates may choose different forms of advocacy: independent or divisional self-advocacy groups; charities or DPOs, usually led by parents or professionals; or they may join a broadly defined 'autistic community' where solo and collective types of advocacy are both present. This latter, somehow unorthodox form of self-advocacy may also involve various ad hoc or permanent collectives where people work with other self-advocates or non-disabled allies.

In this chapter, organisational and extra-organisational forms of self-advocacy will be assessed, with special attention to factors that help or hinder people in different forms of advocacy. In other words, the analysis will aim to appraise the 'pros and cons' of organisations as opposed to other, extra-organisational forms of self-advocacy.

WHY ORGANISATIONS?

Organisations have been central to the development of the modern movement of disabled people (Barnes & Mercer, 2010; Blackmore & Hodgkins, 2012; Hurst, 1999; Oliver & Barnes, 2012). As shown in Chapter 4, organisations are often seen as the most common forms of disability advocacy. As revealed in Chapter 2, previous literature also had a strong focus on organisations and previous studies have provided rich details on how self-advocacy groups and organisations operate. Furthermore, disability organisations are central to advocacy because national and international laws recognise them as representative entities to disabled people. Both the CRPD and several domestic laws (including those in the UK and Hungary) have put DPOs in the centre of policy-making (Birtha, 2014b; Flynn, 2013; Lawson & Priestley, 2013; Stein & Lord, 2010; United Nations Office of the High Commissioner on

Human Rights, 2010): they are regularly consulted by governments when developing new laws, they publish reports on disability policies, they monitor rights, and they are featured in the media etc. The role of DPOs in implementing disability human rights is a core innovation of the CRPD. In fact, DPOs participated actively in the development of the CRPD (Sabatello & Schulze, 2014). The importance of DPOs '*in the monitoring and implementation [of the CRPD] at all levels is both implicitly and explicitly woven throughout the entire fabric of the text*' (Stein & Lord, 2010 p. 697). With the recent publication of General Comment 7 (CRPD Committee, 2018), it is likely that the role of DPOs in the implementation and monitoring of human rights will be further strengthened through the quasi-jurisprudence of the CRPD.

DPOs also proclaim themselves as representative organisations that are '*the voice of disabled people*' (European Disability Forum, 2017). They are seen as entities that can provide expertise specific to disabled people's lived experiences (Stein & Lord, 2010). DPOs have also been major drivers of policy changes in both countries, and it is estimated that there are around 650 to 1000 DPOs working in Britain (Blackmore & Hodgkins, 2012). Similar estimation is not available in Hungary, but it is acknowledged that national umbrella organisations and their member organisations, controlled by disabled people or others include nearly all advocacy organisations active in the disability field (Papp et al., 2014).

Organisations are both well-researched and well-publicised structural forms in disability advocacy (Balázs & Petri, 2010; Bertilsdotter et al., 2015; Bylov, 2006; Chamak & Bonniau, 2013; Chamak, 2008; Ne'eman, 2010; Waltz et al., 2015). Previous studies have often investigated actual advocacy organisations building on a case study approach, providing important insights into how certain DPOs work with self-advocates. However, organisations have been rarely put alongside individual or other extra-organisational forms of advocacy and the relationship between organisational and extra-organisational advocacy remains unexplored. In the present analysis, organisations will be appraised as one possible form of self-advocacy, whilst other options – individual self-advocacy, online communities or other extra-organisational forms – will be also looked at.

There are several reasons why this analysis is necessary. Earlier chapters called attention to extra-organisational self-advocacy which was found to be popular among autistic people. However, it is remains unknown what makes some self-advocates bypass traditional organisations such as DPOs, charities, parent-led organisations or human rights watchdogs while other self-advocates still work inside these structures. Furthermore, the relationship

162

between virtual/online communities, solo self-advocates and formal organisations is also blurry: are these mutually exclusive or complementing options for self-advocates? In other words: do self-advocates join the disability movement both through organisations and as individual advocates? Do individual self-advocates think they are part of the disability movement? Are novel forms of self-advocacy (including online collectives, consultancy, blogging and vlogging, authoring articles and books, petitions etc.) gradually replacing previous, formal organisational work?

The present analysis cannot answer all these questions. However, the inductive approach taken in the study opens the space for the appraisal of organisations in contrast to extra-organisational forms of self-advocacy. The aim is, therefore not to answer all the above questions but to be inspired by them and explore *what organisational self-advocacy means to members of the disability movement as opposed to extra-organisational self-advocacy*.

The research question for this analysis is: **What are the advantages and disadvantages of doing self-advocacy within and without organisations?**

The analysis will be divided into two parts. In the first part, participants' views on organisational vs. extra-organisational advocacy will be appraised. During interviews and focus groups, all participants were asked whether they found extra-organisational self-advocacy possible.

This chapter will offer two separate analyses. First, both organisations and solo self-advocacy will be looked at from the viewpoint of self-advocates. Benefits and drawbacks of working within and without organisations will be presented, based on participants' views.

In the second analysis, self-advocates' involvement in organisations will be assessed by using Arnstein's Ladder of Participation (Arnstein, 1969), a well-known representation of citizen involvement. In this second section, the focus will be only on organisations and how they involve autistic people and people with a learning disability in their work and in their decision-making processes.

For the analysis, content analysis will be employed (Hsieh & Shannon, 2005). Content analysis allows for flexibility when assessing textual data – here, it will be used to identify factors that may be decisive for self-advocates when they choose between organisational or extra-organisational advocacy. Interview and focus group transcripts were used in a fashion similar to previous chapters: the researcher read all transcripts several times and coded data

in NVIVO software. Several 'nodes' were formed in NVIVO which then were further analysed to identify factors. In the analysis, 'pros and cons' will be presented for organisations and extra-organisational[24] work, respectively.

7.1 ORGANISATIONS OR EXTRA-ORGANISATIONAL SELF-ADVOCACY

7.1.1 Factors influencing extra-organisational self-advocacy

Several participants recalled moments when they worked alone as (self-)advocates. At the time of data collection, most autistic participants did much of their advocacy outside formal organisations. All participants with a learning disability worked in groups, although some mentioned times when they had been outside groups. Thus, most participants had experience in doing self-advocacy outside formal organisations.

When asked about their experiences, nearly all participants noted that doing self-advocacy outside organisations is both a possible and valid form of (self-)advocacy. One autistic participant from Hungary even stated '*everyone is doing self-advocacy within the limitations of their individualism*' – pointing at self-advocacy as an everyday practice for people who speak up for themselves or do other 'para-advocacy' practices appraised in Chapter 4. However, another participant in South East England also noted that it is often financial constraints that prompt people to self-advocate alone.

> *Now we don't have any speaking out groups because funding is not there. (…) We need to reach out more to people but it's the funding then, everything's relying on funding. (British advocate in learning disability)*

Indeed, several participants stated doing self-advocacy outside organisations may be a 'necessity' because loneliness and isolation make it difficult for people to find groups. Thus, extra-organisational self-advocacy is not always a choice but – in the absence of self-advocacy groups or support – the only way to exercise self-advocacy.

When asked about self-advocacy outside organisations, one autistic participant responded in an emotional way. The following opinion highlights that even 'solo' self-advocacy have a strong ethos of community, where individuals work and advocate for the benefit of others.

---

[24] In the following analysis, 'solo', 'individual' and 'extra-organisational' self-advocacy will be used as quasi-synonyms because participants also used various similar terms when they discussed the topic. However, it is also acknowledged that not all extra-organisational self-advocates advocate alone. As shown in Chapter 5 (Pathways Model), although many autistic self-advocates work outside organisations as 'individual' self-advocates, they may still be part of a wider 'autistic community'.

In other words, individual or extra-organisational self-advocates do not necessarily work for themselves or alone: often, they work as part of a community, and they work for the benefit of their peers.

> *How do you mean 'doing it alone'??? Everybody who does self-advocacy does it for everyone. It [self-advocacy] is for the community, for the minority… Even those who work alone, they do it for autistics, they are not doing it for themselves. Even if it's two autistic people doing it [self-advocacy] together, they do it for everyone!* (Hungarian autistic self-advocate)

Participants emphasised several features of extra-organisational forms of advocacy. In the following analysis, factors that are seen as limitations, and factors that are seen advantages of extra-organisational self-advocacy will be presented.

7.1.1.1 Limitations of extra-organisational self-advocacy

Several participants noted that self-advocacy outside organisations always faces serious limitations. Most participants mentioned that individual self-advocacy can only have limited impact. It seems that members of the learning disability and autism advocacy movement agree that the more (self-)advocates work together, the bigger the impact it has.

> *I can totally imagine this [individual] form of self-advocacy and advocacy. But you can do it alone only up to a certain level. Obviously, it is going to be less effective, and there is a big difference in the 'size' of it… I mean, if I fight alone, either as a self-advocate or an advocate, I can only do so much unless I am joined by others. (Hungarian advocate in autism)*

Other participants noted further limitations of individual self-advocacy as opposed to collective self-advocacy. Most commonly, participants stated that collective advocacy can achieve more than individuals, for example because they are taken more seriously.

> *You can do self-advocacy alone, but the more people you work with, the stronger voices they are. Because if you work on your own, there's a strong voice, you are speaking up for yourself, but if you speak up with other self-advocates your voice is gonna be twice or 100 times better than campaigning on your own. (UK self-advocate with a learning disability)*

One of the main limitations of doing extra-organisational self-advocacy was claimed to be the lack of impact on policies. For example, several autistic participants stated that self-

advocacy outside organisations may not be taken seriously by authorities or the public in general. Autistic self-advocates are not always seen competent to speak about issues outside their personal autistic experiences.

> *The drawback of this [working outside organisations] is that they are looking at us in a different way, or I should say they are not taking us seriously. For example, when they ask us for an interview then they put different questions. They don't even think that we could comment on, that we can have an opinion on things like this scandal.[25] They do not ask us what we think about it… They invite us for interviews on TV, in newspapers etc. They have seen us several times, that know we can talk and be present in a TV studio. But they hardly ever ask us about things like the law, international issues, scientific stuff, or on professionals. In these things, we are just 'not competent'. (Hungarian autistic self-advocate)*

The most salient limitation of extra-organisational self-advocacy is the limited impact it has. Collective forms of self-advocacy are seen to be greater in their influence on policy-making – however, individual self-advocacy may also entail some advantages.

7.1.1.2 Advantages of extra-organisational self-advocacy

When asked about the reasons for doing self-advocacy alone, several participants pointed out factors that make group work less attractive to self-advocates who then carry on working outside groups. For instance, one participant noted the difficulties group work poses to autistic people:

> *I think sometimes working with a group also can be quite difficult because everyone has their own opinion and some things simply don't get done because everyone is fighting about how they should do or how they shouldn't do it. I think I tend to be within kind of groups like that a lot of times. (British autistic self-advocate)*

Another participant mentioned serious problems self-advocates face when trying to work together in a group. The below statement was given in the context of starting new, autistic-controlled organisations.

> *…we just DON'T KNOW [with emphasis] how to do it [self-advocacy] in a group! The thing is that whenever two or three people come together, we have no clue how to*

---

[25] Here, the participant made reference to a scandal in 2016 when a human rights watchdog organisation found gross human rights violations against autistic people in a residential institution nearby Budapest, Hungary.

166

> *build consensus on what we must stand up for, how to bring our opinions together.*
> *These group dynamics just don't work. (Hungarian autistic self-advocate)*

Importantly, the difficulties of group work do not mean self-advocates have to work alone, or without the support of their peers. Once again, the following opinion implied that not all self-advocates who work outside organisations work on their own and the internet can substantially help to connect with peers.

> *…physically sitting in a room with other people is really hard, that's not going to be*
> *what they [autistic people] want to do. And that's also where the internet helps in*
> *virtually sitting in the same room with someone so that's what is often a lot easier for*
> *us, be able to do things in writing rather than verbally.* (British autistic self-advocate)

Not all participants preferred self-advocacy outside organisations merely because they found working in a group too challenging. In fact, several people stated that it was a conscious decision to avoid joining or establishing an organisation. Many autistic participants voiced strong criticism in both countries about the lack of 'autistic' control over organisations. The lack of opportunities to influence organisational (such as DPO or charity) advocacy is a key problem for many autistic people. In fact, many autistic self-advocates choose to advocate outside organisations because they would like to exercise greater control over their self-advocacy.

> *The reason we decided not to register as a civil society organisation is… well, we saw*
> *the many disadvantages it would bring. And the benefits [of an organisation] are not*
> *that great at all. We didn't want to deal with all the legal and other procedures. Now,*
> *not being a formal organisation, we have the advantage that all we do is really coming*
> *from the bottom-up. And really, everything, the full control is in our hands.* (Hungarian
> autistic self-advocate)

Notably, not only self-advocates said they saw extra-organisational advocacy possible. Some parent advocates highlighted that not all advocacy collectives need a legal form to lobby for changes or to challenge existing structures of power. Similar to self-advocates, some parents may also prefer to advocate outside formally established organisations.

> *I don't need either the X. nor the Y. organisation [names well-known NGOs] to bring*
> *together other parents and form an advocacy network and protect our rights! To*

167

represent our interests before the school principal! You only need NGOs at the point
when you want to challenge someone legally.[26] (Hungarian parent advocate in autism)

Lack of 'full control' over advocacy initiatives was not the only reason why organisations
appeared to be less appealing to self-advocates. DPOs, charities and other formal collectives
may maintain rigid organisational structures where self-advocates face multiple barriers,
including outdated internal rules and bureaucracy. It is possible that such barriers make
people turn away from existing organisations and start seeking extra-organisational
opportunities.

There are very strong internal structures within advocacy organisations[27]. They work
along traditions... and there are lots of internal conflicts in these organisations. And
bureaucracy. Plus they have their founding statues... So people bounce back from
these structures. Anyone who is well-informed and really wants to achieve something
would avoid working in those [organisations]. (Hungarian advocate in learning
disability)

Among the main benefits of working outside organisations, two main issues were
mentioned. First, some participants stated that online self-advocacy, outside organisations,
in the form of personal blogs or vlogs can transmit valuable messages and can also aid more
traditional forms of advocacy.

For those autistic people who cannot hold a conversation or who are simply not
interested in conversations…, well, these people can still meaningfully express
themselves on blogs. Which is cool. This is a good example that autistic people ARE
ABLE [with emphasis] to convey messages about themselves, and this can be
channelled into advocacy as well. (Hungarian autistic self-advocate)

Second, individual self-advocacy can also be impactful if the person self-advocating is well-
known in the community. The following quote asserts that not all individual self-advocates
have the same impact on the public. Leadership skills, popularity or other personal traits can

---

[26] Under Hungarian law, both NGOs and individuals can launch collective complaints (Kezenfogva
Alapitvany, 2018). In practice, legal aid to individuals is often provided pro bono by NGOs and DPOs
that also often cover the costs of legal actions.
[27] In the context of this interview, the participant was discussing national umbrella organisations in
Hungary (controlled by parents).

offer opportunities to be heard outside organisations – however, even for such self-advocates, the voices of their peers are indispensably important.

> *And I think that's probably it, if the person is a big enough name being a self-advocate, saying this is a problem, I'm going through… then they may get listened to but unless you got a big platform that single person is not gonna be heard. They need the voices of everyone else. (British autistic self-advocate)*

Finally, one advantage of extra-organisational self-advocacy was that it allows for more flexibility for those who are not willing to work full time as self-advocates. Indeed, self-advocacy outside advocacy organisations may offer more flexibility for individuals and is less restricted by rules set out in an employment contract.

> *This [extra-organisational self-advocacy] suits those people especially, who love to communicate, are interested in advocacy, but they don't want to make a full-time job out of it, for 8 hours a day, with a fixed salary, a job that fills their WHOLE LIVES [with emphasis]. I think that's the advantage of what we are doing, at least that's how I feel. (Hungarian autistic self-advocate)*

Extra-organisational self-advocacy was mostly discussed by autistic participants, while other participants gave their views mostly on organisations. It is possible – similarly to the assertion of the Pathways Model in Chapter 4 – that extra-organisational self-advocacy is a topical issue in contemporary autistic advocacy, but less so for people with a learning disability. For autistic people, the advantages of extra-organisational self-advocacy often outweigh its difficulties. The main benefit of extra-organisational self-advocacy appears to be the fact that many autistic people do not trust existing organisations, usually controlled by non-autistic people. Self-advocates wish to maintain control over their work or wish to do self-advocacy in ways that may not fit rigid organisational structures.

7.1.2 Factors influencing self-advocacy in organisations

When participants were asked about the benefits and drawbacks of working in organisations, they usually talked about their actual experiences with actual organisations they knew personally. Some autistic self-advocates did not have substantial experience about working within DPOs or charities, so they shared knowledge they gained through other means, for example through following an organisation's work externally through newsletters etc. Nonetheless, this *external* perception of organisations provided valuable observations in the analysis, because members of the disability movement – similarly to

169

other social movements – gain much of their knowledge through already existing organisations or collectives they follow. Organisations usually feature their work in newsletters, online news, magazines, advertisements, social media posts etc. which gives a lot of opportunities to followers to form their opinions about various aspects of an organisation's work. In other words: one does not need to be a formal member of an organisation to form an opinion about it. Indeed, participants made statements about both organisations they were part of and also about organisations they only followed on social media or through newsletters.

7.1.2.1 Disadvantages of organisations

One of the most recognised disadvantages of organisational self-advocacy was its perceived bureaucratic nature. Administrative tasks in formal organisations such as financial and legal administration are seen as serious barriers to those who wish to establish an organisation.

> *Associations do make sense if… obviously, organisations need to be run. You need people who do the financial issues, someone who does the legal work, one for administration, one who organises things, maybe even an office manager, or a boss or president. If you have the right people for all these positions and they can work together, then it makes sense to establish an organisation... (Hungarian autistic self-advocate)*

The leadership of organisations was also contested by several participants, which appears to be a factor why self-advocates are unwilling to work within DPOs or charities. For example, several autistic self-advocates noted the controversy of having non-disabled managers controlling organisations speaking for autistic people.

> *The X. charity is a top-down organisation, it's operating in a top-down way and completely… (…) I mean it's like having men leading a feminist organisation, it's completely mad having non-autistic people leading all these supposedly autistic advocacy groups. (British autistic self-advocate)*

Non-autistic leadership in organisations speaking for autistic people seems a major factor in explaining why charities and other organisations may not appeal to self-advocates. Autistic people may see such organisations breaking the rule of 'nothing about us without us'.

> *I think historically there's been an awful lot of stuff that was about us but without us. And that's still the case with the majority of the charities, services, organisations that*

are designed to support autistic people, in any way, shape or form, are primarily run
by neurotypicals and people who don't necessarily have the insight of our common
experiences, so this a quite dodgy ground to get... (British autistic self-advocate)

The leadership of organisations was not the only issue in the context of control. As shown in Chapter 2, some charities and DPOs have been making changes in their organisational structures and are electing self-advocates to be Board members. However, this strategy was criticised by several participants as not being substantial enough, with one British autistic participant calling it '*window-dressing'*. The following statement by an experienced professional advocate in Hungary also demonstrated that the formal election of self-advocates to charity boards may not be enough for profound changes.

Electing someone [with a disability] to become a Board member has no impact… (…)
Why? They [organisations] can fill in any position by anyone if the right spirit is not
there. The spirit that they REALLY [with emphasis] care, that they really want to bring
out the most of people. Until this is not there, it's all just paperwork. It's just a show.
(Hungarian advocate for people with a learning disability)

Power imbalance in charity Boards can be a serious factor that hinders self-advocates from taking control. For example, even when elected to a Board, disabled Board members may still form a minority.

It's important that a person with a learning disability is on the Board. But then again,
we always say we need people with a learning disability on the Board so now we've
got XY [names person] but that's still not good enough. Because that's two [people
with a learning disability] but there's still four or five people without! (British advocate
in learning disability)

Joining organisations may not be an attractive option to those self-advocates who want to see advocacy controlled by disabled people. The advocacy existing organisations (DPOs or charities) do is sometimes seen contentious by self-advocates. For example, one autistic woman in Britain said: '*organisations that do campaigning, people don't always agree that*
they campaign for the right things (…) I don't, I can't say where advocacy is here, but I can
see it is not where it should be.' Other participants made similar statements in both countries

about organisations controlled by non-disabled people, including some organisations that had self-advocates on their Board.[28]

Organisations are seen by many self-advocates as not giving enough opportunities to self-advocates to gain control over initiatives. Most organisations mentioned by participants were mentioned in a negative context, as examples for charities or NGOs that are 'not doing enough'. Furthermore, self-advocates may think that administrative and organisational duties are greater in organisations than in other forms of self-advocacy, and some may see this as barriers to start new organisations that are controlled by self-advocates.

7.1.2.2 Advantages of organisations

All participants agreed that organisations outweigh other forms of self-advocacy in that they are recognised by the public as being representative voices of disabled people and/or their families. Representative organisations were seen to have a much greater impact than individuals' initiatives. One autistic self-advocate used football as a metaphor to explain the difference, but also noted that 'big' organisations are not always as progressive as small ones. Size matters but size is not the only thing to look at.

> It always has a greater impact when something comes from the work of a bigger organisation. It is like going to play football with your mates in the park as opposed to Real Madrid playing against Barcelona. It is possible that the former has more merit in it and it is more progressive but still... Organisations are taken much more seriously. (Hungarian autistic self-advocate)

---

[28] In the context of organisational control by parents, all self-advocates in this study stated openly that they preferred speaking for themselves and not parents speaking for them. This finding reasserts previous studies that emphasised the differences between parent-advocacy and self-advocacy (for example Bylov, 2006; Goodley & Ramcharan, 2010; Reindl, Waltz, & Schippers, 2016; Waltz, 2013; Wehmeyer, Bersani, & Gagne, 2000). On the other hand, several autistic participants and participants with a learning disability also mentioned that parent-led organisations were potentially strong allies to self-advocates. In the context of speaking about parents, a British self-advocate with a learning disability stated: '*I usually like to speak for myself! Get my voice heard. But sometimes I want someone to help me on the challenging issues but I think I'm getting much better at speaking up for myself, I am getting a whole lot better now*.' This statement is emblematic to many other self-advocates' opinion in this study who saw parents' role crucial in advocacy. A full analysis of participants' views on parent-advocacy in the context of self-advocacy is outside the possibilities of the present report.

Some participants contemplated starting new, self-advocate-controlled organisations to achieve greater impact in advocacy. However, starting new organisations is seen to be involving a lot of difficulties.

> *So, when exactly are autistic people going to form their organisation to speak for their interest? I think we need enough autistic people to start with, people who have eight hours a day to work for it, to work full time for it. Just as we have said before, it is not enough to wish this, not enough to decide [to start an organisation], it requires big, big energy!* (Hungarian autistic self-advocate)

Organisations were also seen as decidedly helpful for several participants, for instance when they ran programmes or distributed materials that helped both parents and self-advocates. Being supportive towards advocates and self-advocates was said to be one of the most important traits of organisations.

> *To me they are wonderful organisations, also X. organisations, and I use their resources quite a lot, and to me, as an independent advocate their role is very important. Obviously, their advocacy is coming from a different [direction] (…) their role is extremely important but also from a slightly different angle to be able to provide support to people who have a barrier in some way, whatever it is, whichever organisation they are…* (British advocate in autism)

Participants with a learning disability also pointed at the support organisations gave to self-advocates. In fact, one participant, leader of a self-advocacy group that is run by a parent-organisation stated that their group could not exist without the organisational background. Self-advocates with a learning disability strongly rely on the support provided – and funded – by organisations.

> *This [self-advocacy] group wouldn't work without X. organisation. It is them who organise the programme for us. If we did this without them, it wouldn't work. They help us. (Hungarian self-advocate with a learning disability)*

All self-advocates with learning disabilities agreed that self-advocacy was first and foremost a collective experience for them, exercised in organisations and/or in self-advocacy groups. Several participants with a learning disability mentioned the support they received in self-advocacy groups, either from peers or from support workers. For people with a learning

disability, organisational forms are much more preferable than extra-organisational work, because most self-advocates get the support they need from organisations.

> *Researcher: How were you helped in groups?*
>
> *Self-advocate: Now I am a little bit more independent. In everything. I can walk back home alone. Even if it's really dark, alone. Okay, sometimes someone else walks with me, because I am afraid alone, but then I can ask someone. (…) I got help in these groups. (Hungarian self-advocate with a learning disability)*

Another core feature of organisations recognised by several participants was that organisations control resources. They can allocate funds to support local self-advocacy or speaking up groups. In the following statements by two self-advocates, big charities were pictured as rich and resourceful entities that can afford to support various different local groups – some of which are different from groups controlled by self-advocates.

> *Researcher: What do you think of X. big charity?*
>
> *Self-advocate 1.: They've got more money than we've got [at our organisation]!!!*
>
> *Self-advocate 2.: They do more like very close supporting, don't they? [laughs] How to say it. A lot of group-support sort of thing. Some of it is similar to us [names own organisation] but some of it is very different.*
>
> (British self-advocates with a learning disability)

Indeed, organisations support and control many self-advocacy groups. In the view of a Hungarian professional advocate in learning disability, the national umbrella organisation (controlled by parents) runs almost all the self-advocacy groups in the country. One self-advocate with a learning disability in Budapest gave a straightforward explanation about the possibility to become independent a parent-controlled organisation.

> *Researcher: Could you get funding for your[self-advocacy] group, without X. organisation?*
>
> *Self-advocate: I don't think so. Where from? Tell me! We can't. The X. organisation is doing it nicely for us. (…) Anyone can try to do it [without X. organisation] but it is futile, won't work. They will fail. How could they do it? You need a place for meetings, you need people, someone needs to organise things… that's money and time! To pay for the room, you can't do without them. (Hungarian self-advocate with a learning disability)*

Organisations are also dominant in self-advocacy because they control much of the existing resources. In the words of one self-advocate, organisations were '*where the money was'* in self-advocacy, and if one would like to initiate '*nice things'* then organisations offer opportunities.

'*If you are a self-advocate you can speak up for yourself, but if you're part of a self-advocacy organisation, that's where the money is needed probably, for an organisation, to get by and get around and to be able to spend it on nice things that make self-advocacy work'.* (British self-advocate with a learning disability)

One self-advocate compared a well-known British charity to other advocacy initiatives. Here, a leading organisation appeared as a 'great beast' as opposed to other forms of self-advocacy, including the extra-organisational activism the interviewee did.

It [names charity] is completely inequitable in terms of the pay scales. And the way it operates!... It's like an enormously great beast. (British autistic self-advocate)

7.1.3 Conclusions – organisations vs extra-organisational advocacy

To conclude, organisations are much more salient in self-advocacy than other, extra-organisational forms of advocacy. Although there are clearly some benefits of self-advocacy outside organisations, benefits of working in an organisation may be more appealing (Table 7.1).

	Self-advocacy in organisations	Extra-organisational self-advocacy
Pros	More support from the organisation More resources available Bigger impact on policies More support from peers (learning disability)	More flexibility Less administration and bureaucracy Fewer difficulties in group settings (autism)
Cons	Less control over initiatives Non-disabled managers leading organisations More bureaucracy and more rigid rules	Limited impact Not being taken seriously

Table 7.1 Organisational vs. extra-organisational self-advocacy

Extra-organisational forms are often chosen by self-advocates out of necessity, for example, because there are no other options where they live, or because they find traditional forms of group work (such as lengthy meetings) too demanding. The internet offers an opportunity for many autistic people to join peer groups through email, Skype or other means, and blogging and vlogging are also popular options for those who want to share their personal experiences. Importantly, one of the greatest advantages of extra-organisational advocacy

175

is that people can work outside hierarchic and rigid organisational structures, with more flexibility in terms of workload and time devoted to advocacy. Many autistic people choose extra-organisational self-advocacy because they want to remain in control over what they do when they advocate.

On the other hand, nearly all participants noted strong limitations of extra-organisational work. For people with learning disabilities, extra-organisational work has virtually no benefits, because outside organisations (including formal groups) they would lose much of the benefits they get: support from others. Existing organisations (charities, NGOs, parents' organisation, DPOs, umbrella organisations etc.) are often perceived as lacking autistic leadership, and many autistic people heavily criticise the advocacy these organisations do.

Furthermore, organisations control most of the resources available in the movement, which make them indispensable, because they can establish and run self-advocacy groups. Organisations may also be seen as 'enormous beasts' that are slow to change. Electing new Board members with learning disabilities or autistic people is only 'window-dressing' for self-advocates who would like to see more substantial changes in the control of organisations. Several autistic participants also noted that launching new advocacy organisations would require resources not available for autistic people.

7.2 Nothing About Us Without Us – Involvement in organisations[29]

Participants were also asked to assess the participation of self-advocates within organisations and/or within the disability movement as a whole. This part of the study built on findings of Chapter 5 (Pathways Model) and assumed that organisations such as charities, parent-run organisations, professional advocacy organisations, umbrella NGOs and other DPOs are core players of the learning disability and autism advocacy movement.

Furthermore, this analysis also reflected on Article 33 of the CRPD that makes it mandatory for States Parties to involve disabled people in monitoring and implementing the CRPD, through 'representative organisations' of persons with disabilities. Thus, the present part of the analysis is also an assessment of how 'representative' organisations mentioned in the CRPD are involving self-advocates in their own work.

It was assumed that participants have a personal experience in how such organisations or the disability movement as a whole involves self-advocates in their work. One limitation of

---

[29] The findings presented in this section were already published in Petri, G., Beadle-Brown, J., & Bradshaw, J. (2017). "More honoured in the breach than in the Observance"—Self-advocacy and human rights. *Laws, 6*(4), 26.

the following analysis is that the question about the involvement of self-advocates was left intentionally somewhat vague. Instead of restricting the question to one or two specific organisations, interpretation of the questions was left open. Some participants answered questions building on their own personal experience at an actual charity or NGO, while other participants made broader observations about the learning disability and autism advocacy movement. Therefore, the analysis presents data about both how organisations and the movement as a whole involve self-advocates in its work.

To aid participants' understanding and to get data-rich answers, the question the researcher asked also included reflections on the general population. For example, '*How are British autistic people involved in decisions about them?*' – this allowed participants to reflect on the question by placing their answer in a broader societal context.

For assessing the participation of self-advocates in DPOs and in the movement, a well-known visualisation was used. Arnstein's Ladder of Participation (Arnstein, 1969) is a widely referenced conceptualisation of citizen involvement in decision making. (See Appendix 1) Using the Ladder of Participation in the disability context is not unknown, for example it has been used when looking at the involvement of autistic people in research (Pellicano, Dinsmore, & Charman, 2014) and was referenced when DPOs' involvement in the monitoring of the CRPD was looked at (Birtha, 2014b). The Ladder of Participation offered itself as a particularly useful tool in the study because of its accessibility and relative simplicity. Nonetheless, for participants with a learning disability, a more simplified version was used with only five steps on the ladder (as opposed to eight steps in the original concept). The Ladder, originally developed in the English language, was translated into Hungarian by the researcher, including into easy-read Hungarian for participants with a learning disability.

All participants were asked to assess where self-advocates stand on the ladder within DPOs representing them or within the disability movement as a whole. (Prompts depended on participants' backgrounds, for example, their personal experiences in DPOs.) Many participants found it challenging to generalise but with the exception of two participants all agreed to locate self-advocacy on the ladder. Several participants were unable to point at one actual step on the ladder, instead provided approximate locations, for example 'somewhere down here' or 'somewhere in tokenism'.

Findings were consistent across all subgroups and the two countries, and not different between learning disabilities and autism: self-advocates have a low to moderate level of

177

participation in organisations representing them, away from 'citizen participation', mostly standing around informing, consultation and placation. The overwhelming majority of participants saw self-advocates being on levels of tokenism within organisations representing them.

Below placation… (…) I think generally we would be at the level of tokenism. We tend to be listening but we actually don't give enough options for them and the support to be truly the way it should. (British professional advocate for autistic people)

Some participants noted that generalisation is difficult to make, but overall patterns are still obvious for those working within organisations, both in autism and in learning disability advocacy.

Participation is always individual, how you actually involve them, it is a process, but I'd say the average person with a learning disability in advocacy is there in the middle, in tokenism at best. (Hungarian professional advocate for people with learning disabilities)

Autistics are down there in therapy in the general population, and in advocacy organisations may be on the level of being informed. (Hungarian autistic self-advocate)

One autistic self-advocate in Hungary pointed out that the disabled people's movement itself is yet to comply with the CRPD: *'…actually, there is the saying "nothing about us without us", which I think is in the Convention itself. This means they [organisations] have to involve us so that we are there in the decisions taken about us. But this is not happening at all*.' Some participants also saw possible explanations for the tokenistic involvement of self-advocates in organisations.

I still think this would be within the degrees of tokenism but slightly up, in the middle of this (consultation). And it's interesting you mention charities because I do think sometimes there's a hidden agenda to speak for these people rather than allow them to have a voice themselves. There are some great charities out there, but there's also a lot of… careerist out there, people who made a quite comfortable career with a relatively good income from speaking on behalf of them. (British advocate for people with learning disabilities)

Several participants stated the level of participation was variable over time. According to a Hungarian professional advocate for people with learning disabilities, '*we are trying to bring it up to partnership level in our organisation, but it is just not working yet*'. In some cases, improvements may happen, but sometimes there is a setback in progress within organisations.

> *X. organisation moved toward citizen control and pulled back to placation and I think has slipped now to consultation in how it works. In terms of the broader disability movement insofar as there's one, the problem is that intellectual disability just hasn't managed to get any purchase at all.* (British professional advocate in learning disability)

For some autistic self-advocates in both countries, the progress in participation is happening, although only sporadically and slowly: '*We are only starting to reach the level if informing if they listen to us at all. Although we see there are already some organisations where they take us seriously and don't just tell us "you little stupid thing, what do you want?"*' (Hungarian autistic self-advocate)

Progress was also mentioned by another participant who pointed at good practices within the disability movement.

> *I think in advocacy, for the most part, they would be in the middle. At the level of informing. What we are aiming toward is partnership (…) There are isolated pockets where there are good practices where it is moving away from tokenism.* (British autistic self-advocate)

There were also participants who saw the participation of self-advocates in DPOs or charities largely at the lowest level, around manipulation, with 'no power'. For instance, another British autistic self-advocate stated '*As I said I don't feel part of the community, and I struggle with the language of intervention but the main trope is still around, the behaviour analysis and… equally, there's … At large the establishment still has its power, so we are there, down [no power].*'

A notable exception to the majority opinion was that – consistently between the two countries – there were several self-advocates with a learning disability who saw themselves being on the level of citizen control. For example, two British self-advocates with learning disabilities stated:

179

Self-advocate 1: Now? Definitely now at the top! When I was in the [care] home, back then, more down here, halfway through, therapy and manipulation. I felt I weren't in control. And I was pushing them limits to get my control. Because I knew what I wanted and I KNEW [with emphasis] what I wanted to do but it's like how do I say it unless I'm doing something wrong.

Self-advocate 2: I was down there in the past, NO POWER [with emphasis] but now up to partnership and control. Jumped from manipulation and now I am in the green.

(British self-advocates with a learning disability)

Similarly, a Hungarian self-advocate with learning disabilities claimed *'I think I am up here on citizen control because I get the information I need and I have worked a lot to achieve this so I can also help others to achieve it.'* This statement echoed finding of several previous studies (for example Atkinson, 2006; Goodley, 2000; Tilley, 2006a; Walmsley, 1993 etc.): self-advocacy groups for people with a learning disability can provide meaningful control for people over certain aspects of their lives, including over their advocacy work. This must be recognised along the broader observation made by most participants about tokenism in organisations.

The analysis showed clearly that self-advocates' involvement in organisations (and the advocacy movement as a whole) is around the level of tokenism and informing, with only 'pockets of' good practices. Opinions about tokenism were consistent between professional advocates, parents and self-advocates, and also consistent between the UK and Hungary.[30]

7.3 CONCLUSIONS

The analysis further confirmed that organisations are central in contemporary self-advocacy. However, the involvement of self-advocates within organisations was only at the level of tokenism and informing, far from meaningful control over how organisations were. Many

---

[30] As stated before, human rights mechanisms and the CRPD are of particular importance in the context of organisations. The CRPD puts DPOs in the centre of human rights monitoring in Article 33(3) and Article 4(3). In order to assess whether human rights mechanism are making a difference in present-day self-advocacy, the study also looked at participants' opinion about the CRPD and human rights laws in general. Questions were asked about participants' knowledge of human rights laws (such as the CRPD), and it was also asked whether participants found human rights useful in their advocacy. It was found that the overwhelming majority of participants – including self-advocates, parents and professionals – had very limited knowledge of human rights laws and the CRPD. Most participants saw human rights as '*big, vague ideas in the distance' (British autistic self-advocate).* Importantly, advocates and self-advocates strongly agreed that palpable societal changes initiated by the CRPD are yet to be seen (Petri, Beadle-Brown, & Bradshaw, 2017). This finding suggests that the CRPD has not made an impact on the tokenistic involvement of autistic people and people with a learning disability in organisations speaking on their behalf.

180

participants saw the leadership of existing organisations seriously problematic, lacking meaningful control by both autistic people and people with learning disabilities. Initiatives to bring in self-advocates to become Board members of organisations was seen 'not enough' or 'window-dressing' by many participants. Several people noted that such changes did not tackle the core problem of power imbalance between disabled and non-disabled people within autism and learning disability organisations. On the other hand, several advocates and self-advocates suggested that organisations were indispensable, because they supported and ran the large majority of self-advocacy groups in both countries.

Many of those who pursued extra-organisational self-advocacy – mostly autistic people – did so out of necessity. They either found traditional self-advocacy meetings difficult to join, or they thought organisational structures were too rigid and bureaucratic for their needs. Individual and online forms of extra-organisational self-advocacy are seen valid and often helpful in informing the public, but there is a consensus that such advocacy initiatives can only achieve limited impact.

The analysis also found that self-advocates' participation in the work of organisations and the disability movement as a whole is far from meaningful. Professional advocates, parents and self-advocates all agreed (consistently in both countries) that the involvement of autistic people or people with a learning disability is usually at the level of tokenism. This finding also offers an explanation about why many autistic people bypass big organisations and choose to self-advocate in ad hoc, informal or online collectives, or alone.

To reiterate the main research question of this study – '***What are the factors that help or hinder self-advocates in the disability movement?***' – the present analysis found that existing organisations carry both supporting and hindering factors for self-advocates.

Supporting elements of organisations include the allocation of resources to speaking up and other types of self-advocacy groups. It can be assumed that without organisations and the support they give many self-advocacy groups would not exist. On the other hand, organisations also pose a serious barrier to self-advocates, because nearly all existing organisations in both countries (and internationally, see Chapter 2) are run and controlled by non-disabled people. Organisations controlled by non-disabled people often do advocacy that seems contentious to self-advocates, especially when coupled with tokenistic involvement of disabled people.

Organisations seem to be the 'Catch 22' of present-day autistic and learning disability advocacy. Their nearly total control of resources makes them necessary for self-advocacy groups to survive – on the other hand their lack of control by self-advocates drives many people away who seek other opportunities and pursue self-advocacy outside these organisations.

8   CHAPTER EIGHT – CONCLUSIONS AND DISCUSSION

This chapter will bring together the main findings of the study and will also offer theoretical and practical implications for future work. After a brief overview of the key findings, in the second section, the main research question will be answered by looking at barriers and facilitators of self-advocacy in the contemporary learning disability and autism advocacy movement. Then, a new conceptualisation will be applied to the self-advocacy movement by using the Community of Practice approach. Finally, implications for further research will be appraised.

8.1   CORE FINDINGS OF THE THESIS

In order to assess self-advocates' position in the contemporary disability movement, this study started off by conceptualising what self-advocacy meant to members of the movement. It was found that terminology used by advocates and self-advocates was often erratic which hindered a clear understanding of even the very terms 'self-advocacy' and 'advocacy'. Definitions and meanings of self-advocacy and its synonyms also lacked consensus among participants. Most people acknowledged that concepts of 'advocacy' and 'self-advocacy' were highly individual, with 'everyone having their own' definitions. On the other hand, there was an agreement that advocacy and self-advocacy covered 'speaking up' which formed a common ground between definitions employed by members of the movement.

Practices are shared

In the absence of a clear and consensual definition of self-advocacy, a practice theory-inspired analysis was carried out that looked at regular activities advocates and self-advocates do. In Chapter 4, the analysis found convincing evidence that an overwhelming part of everyday practices in advocacy and self-advocacy overlap. In fact, it was asserted that disabled and non-disabled members do largely similar activities as part of their everyday advocacy. Thematic analysis found that regular, routinely done practices include

- informing and being informed;
- being in the community;
- various media-related practices, including the production of media content (both online and offline);
- speaking up;
- administration and bureaucratic duties.

183

Media-related practices, being in the community and sharing information (under the label 'informing and being informed') were seminal practices for all advocates and self-advocates, while administration and bureaucratic duties were less relevant for people with a learning disability. Thus, it is this the assertion of the present study that self-advocacy goes well beyond merely 'speaking up', in fact, practices other than 'speaking up' may be much more regular in people's lives. Knowledge and learning were found to carry particular importance for the empowerment of self-advocates, with some notable differences: whereas for many autistic self-advocates much of this learning and information exchange takes place in a vaguely defined (online and offline) 'autistic community', for self-advocates with a learning disability gaining skills is related mostly to traditional (offline) self-advocacy groups.

The practice theory-inspired analysis led the study to the conclusion that the autism and learning disability advocacy movement may be similar to a Community of Practice (or may be composed of various communities of practice). Communities of Practice (Wenger-Trayner & Wenger-Trayner, 2011) are united by (a) common theme(s), (b) a strong sense of community (constituted by joint activities, discourses, shared information and support between members) and (c) shared practices. These three criteria match the findings of Chapter 4 and it can be assumed that the autism and learning disability movement may be seen as Communities of Practice.

Practice theory also prompted us to propose a new definition of advocacy and self-advocacy that takes into account the broad range of practices found in the analysis: '*advocacy and self-advocacy are a collection of complex and routinely executed actions embedded in everyday practices, that may or may not result in speaking up*'. It was found that practices in (self-)advocacy are not always clearly separated from practices people routinely do, in fact, it was proposed that many practices are embedded into other daily routines. Here the importance of tacit knowledge and tacit learning was suggested.

The new, practice-oriented definition of self-advocacy also allowed us to look at hierarchic relationships between practices. It was proposed that both the availability of *skills* and *resources* to do certain practices may influence self-advocates' position in the disability movement. Importantly, it was asserted that if resources and skills are available, then most advocacy practices could be done by any of the historically separated groups of advocates such as parents, professionals or self-advocates. Therefore, it was found that the position of

self-advocates in the movement is strongly influenced by the resources and learning opportunities available to them.

Pathways to (self-)advocacy

Chapter 5 then set out to investigate advocates' and self-advocates' typical routes to doing (self-)advocacy. The analysis found that both for parents and self-advocates, advocacy was a necessary reaction to oppression and injustice, and in both groups solidarity and helping others was an important motivation in their initial decision to work as (self-)advocates. For autistic people, getting their autism diagnosis and then finding autistic peers were of particular importance. For professional advocates, the route to advocacy was different from the other two groups, as most professional advocates saw their job as a stage in their professional careers. On the other hand, nearly all professional advocate participants in this study talked about family relationships to disabled people. This finding implied that solidarity and their personal motivation to fight against injustice may be rooted in their personal experiences, outside strictly understood professional career paths.

The chapter concluded by proposing a Pathways Model, a mapping of typical pathways to self-advocacy. In the Pathways model, three forms of self-advocacy were offered:

1) **Autistic (online) community**. A relatively new form of self-advocacy was proposed, a form that several autistic participants referred to as the 'autistic community'. The autistic community (or autistic communities) was (were) found to rely heavily on the use of the internet by their members, giving the world wide web a particular salience in the context of collective autistic self-advocacy. It was suggested that much of present-day autistic self-advocacy is happening through such (both online and offline) autistic communities. These communities do not have a strict and formal membership but work in novel ways that encourage people to engage with their peers flexibly. There was no indication that such (online) community may be present for people with a learning disability.

2) **Self-advocacy groups**. The Pathways Model proposed that traditional self-advocacy groups still have a strong relevance in the contemporary disability movement. These groups may operate independently or inside charities or in other types of DPOs. The membership of self-advocacy groups is composed of people with a learning disability and autistic people. Self-advocacy groups include various speaking-up groups, peer support groups as well as self-advocacy divisions of charities and other NGOs. Importantly, the management of these groups is often carried out by non-disabled people.

185

3) **'DPOs and charities'.** This third form of self-advocacy received a central position in the Pathways Model and marked organisations that are controlled by professionals or parents. It was suggested that charities and DPOs of various kinds were central in the contemporary disability movement, for example, because they have a large membership, more resources and they receive bigger media attention. These organisations often work closely with governments or state authorities, and they also have the closest ties with international organisations such as international DPOs, European Union bodies or the United Nations. Notably, many of these DPOs and charities are de facto service providers for disabled people.

Resources and self-advocacy

The study then went on to investigate how the availability of resources impacts the way self-advocates work and participate in the disability movement. It was found that financial resources were a necessary prerequisite of self-advocacy because self-advocacy itself 'costs money'. For example, it was asserted that self-advocacy (and advocacy in general) involved often substantial costs, because support workers, venues, travel and other expenses need to be covered. Lack of financial resources may make it difficult if not impossible to organise self-advocacy meetings or to support self-advocates.

Furthermore, it was found that poverty and low household income may seriously hinder many people from joining self-advocacy. Maslow's hierarchy of needs was cited by participants in both countries as a relevant predictor of who 'can afford' to engage with advocacy. It was claimed by parents, professionals and self-advocates as well that people may be unable to commit to self-advocacy until their fundamental needs (food, housing, clothing) were covered. In fact, it was found that people living in poverty or in low-income households were usually locked out of opportunities to join self-advocacy. People living in rural areas or in areas with inaccessible/expensive/scarce transport may also be cut off from self-advocacy groups. Several participants in both countries suggested that only those can join organised forms of (self-)advocacy who have a certain, secure financial background. This finding suggests that present-day disability advocacy may be run mostly by 'those who can afford it'. This finding suggests that the disability movement that is built on the foundation of equality and emancipation is, in fact, a movement maintaining gross economic inequalities. Social class may be a strong predictor of who can join or get leadership positions in organisations or the movement.

186

Data also suggested that very few paid positions are available to autistic people and people with a learning disability, and self-advocates are often expected to work for free. The uneven distribution of resources in the movement clearly favours non-disabled advocates (professionals or in some cases parents), although salaries of even paid advocates are seen to be low.

Organisations and new forms of self-advocacy

In Chapter 7, the study found that self-advocates' involvement in disability organisations and in the movement as a whole was mostly tokenistic. Participants in both countries agreed that autistic people and people with a learning disability were rarely included meaningfully in the running of advocacy organisations speaking for them.

The importance of this finding is difficult to overestimate: it appears that much of present-day learning disability and autism advocacy is done about disabled people but without disabled people. This finding recalls earlier criticism voiced by academics and self-advocates (for example Aspis, 2002; Aspis, 1997; Dawson, 2003; McGuire, 2012; Ne'eman, 2010). It was also suggested by participants that although some good practices are developing, these are rather just 'pockets', without a systemic impact on the movement. Participants also stated that the election of autistic people or people with a learning disability to boards of charities or DPOs have not changed substantially the status quo.

The study also looked at the 'pros and cons' of working within or without organisations. Organisations (including charities, DPOs, NGOs and various other legal forms of organisations) carry certain features that make them less appealing to new self-advocates. For example, many participants (including professional advocates and autistic self-advocates) said they thought organisations were bureaucratic. Others claimed many DPOs maintained rigid structures that may deter innovation. Several participants thought it was highly problematic that organisations are not controlled by autistic people.

These may be some of the reasons why many autistic self-advocates prefer to work outside organisations, for example in (online) communities or as freelance, independent, consultant self-advocates. Several self-advocates and some parent-advocates also suggested that it was possible to work collectively with peers outside organisations. This highlights the relevance of the Pathways Model that mapped a salient form of self-advocacy ('Autistic community') that is outside off-line self-advocacy groups and charities/DPOs. Importantly, whilst autistic self-advocates saw it possible that they work outside formal disability organisations, such

187

claim was not made by participants with a learning disability. It was found that traditional self-advocacy groups for people with a learning disability were still a relevant and much-needed form of disability advocacy. Indeed, several participants suggested that organising meetings, raising funds and supporting self-advocates before, during and after meetings can only be managed by formal organisations.

Importantly, despite new forms of self-advocacy outside organisations, DPOs, charities and other traditional, formal advocacy organisations are still central to the movement for several reasons. For example, formal organisations control most of the resources available in disability advocacy and they run most self-advocacy groups. Also, they are closely connected to governments and authorities, and their importance is further emphasised by human rights laws that require '*representative organisations of disabled people'* (CRPD Article 33(3)) to take part in policy-making. Several participants noted that only 'big organisations' are taken seriously in the context of policies or disability rights, while independent self-advocates are usually expected to talk about their own experiences and not on behalf of others.

8.2 THE POSITION OF AUTISTIC AND LEARNING DISABILITY SELF-ADVOCACY IN THE DISABILITY MOVEMENT

This study set out to investigate the position of self-advocacy in the contemporary disability movement. In the face of findings of this study, it can be asserted that self-advocates are far from being included in the disability movement: their position is marginal even in well-established organisations speaking on their behalf. The study showed clearly that a significant part of contemporary self-advocacy happens outside organisations, for example in online communities, informal collectives, or through independent self-advocacy such as the work of freelance/consultant self-advocates. The study also found that organisations themselves marginalise self-advocates by only superficially involving them in the control of their everyday work.

There appears to be a 'cognitive gap' within the movement where those with a 'cognitive difficulty' (learning disability or autism) are systematically discriminated against: they are less likely to be paid for their work, they hold fewer paid (including leadership) positions, and they are likely to be involved in organisations only in tokenistic ways.

188

8.2.1 Barriers to self-advocacy

At the beginning of this study, the research question was proposed: **'What are the factors that help, and barriers that hinder self-advocates within the disability movement?'.** Based on findings, several such factors can be presented.

Barrier 1: Economic barrier

The lack of available resources is one of the major barriers self-advocates face in today's disability movement. Most resources available for disability advocacy are distributed by organisations controlled by professionals and parent-advocates who set the priorities for organisational budgets, including who gets paid for their work.

Self-advocates live precarious lives. Many potential self-advocates, autistic people and people with a learning disability live in poverty which makes it very difficult to join collective (self-)advocacy. Many self-advocates choose to work despite not being paid for it (or paid insufficient amount – see the theme 'funny amount' in Chapter 6.). It appears that many organisations maintain double standards: whilst some advocates get paid for their work, others do not. In examples mentioned by participants, self-advocates were regularly expected to work pro bono even in projects where others get remuneration for their work. It is very likely that there is a competition for available resources within organisations that act as *de facto* funding bodies of contemporary self-advocacy. This competition seems to be won over and over again by non-disabled advocates who occupy most high-level positions in disability organisations in both countries.

The lack of available resources, however, is not a factor entirely internal to the disability movement. Even if organisations decided to pay self-advocates, most potential self-advocates would still be hindered from organised forms of advocacy. Poverty, exacerbated by neoliberal state policies across Europe, including in the UK and in Hungary (Dowse, 2009; Malli, Sams, Forrester-Jones, Murphy, & Henwood, 2018; Mladenov, 2015; Mladenov & Petri, under review; Runswick-Cole, 2014; Runswick-Cole & Goodley, 2015) is probably the greatest barrier autistic people and people with a learning disability face when they attempt to join self-advocacy collectives. A recent systematic review found that austerity has deprived people with a learning disability of support that enables autonomy, choice and social participation (Malli et al., 2018).

Barrier 2: Organisational practices

Another major barrier for self-advocates is the organisational practices and conventions of disability organisations. Organisations dominate disability rights advocacy in both countries (Balázs & Petri, 2010; Oliver & Barnes, 2006; Papp et al., 2014; Slorach, 2014; Trevisan, 2016) and they often involve self-advocates in their work in tokenistic ways. A recent study reported that disabled people in several European countries saw DPOs influenced by an 'elite', that is '*powerful, well-resourced and well-known individuals*' (Šiška, Beadle-Brown, Káňová, & Kittelsaa, 2017). The tokenistic involvement of self-advocates in the work of organisations representing them constitutes a form of social exclusion.

Organisational structures such as standing rules for governing bodies, funding traditions, internal rules and various other written and unwritten conventions regulate how disability organisations operate. Such structures may strongly resist progressive changes. It is the assertion of this study that disability organisations resisting organisational change constitute an important barrier for self-advocates. Such resistance can be palpable in discriminatory practices, for example when organisations allow or even invite advocates to work with them in projects but then refuse to remunerate them while other advocates working in the same project get paid. The salience of organisations as barriers is even stronger because the study found that many people would find it impossible to do self-advocacy outside these organisations (or without their help). This means that most self-advocates today only have the opportunity to work inside organisations that both support and systematically marginalise them.

Contemporary disability organisations may be seen exemplifying the 'iron law of oligarchy', a theory developed by German philosopher Robert Michels in his account on political parties (Michels, 1962). Michels investigated the organisational structure and democratic procedures in political parties and found that even socialist parties that presumably built on democratic values as opposed to more conservative parties, maintained hierarchic structures with strong leaders. The 'iron law of oligarchy' theory asserted that most organisations, even if they started off on democratic grounds, eventually became oligarchic. Bureaucracy and the division of tasks, and centralised hierarchy were suggested as factors that contribute to maintaining these structures. Michels also claimed that the larger organisations become the '*greater the degree to which power is concentrated*' (Giddens, 1989 p. 290). The 'iron law of oligarchy' is a useful theory here, because it encourages us to look beyond what organisations proclaim about themselves and look at how they maintain

existing structures of power. If 'big' DPOs and charities are central to current disability advocacy both for their role in supporting self-advocates and for lobbying governments, but at the same time these organisations resist change, then self-advocacy faces a daunting perspective. Self-advocates may either try and work outside these organisations (as they often do today) or else they have to attempt to initiate meaningful changes from inside organisations, trying to challenge the iron laws of oligarchy. Findings of the present study allow giving some considerations to the latter option, to be explored in the last section of this chapter.

Barrier 3: Lack of support

Several participants noted that the more support self-advocates need the more difficulties they may face because of financial constraints. In other words: in an organisational context where resources are low, it is likely that people with higher support needs will find it more difficult to get the help they need, partly because it would require the allocation of more money. It was found that support to self-advocates is far from optional. On the contrary: support is necessary for the constant learning, communication and empowerment of self-advocates. Self-advocate participants regularly stated that they found the lack of support disabling.

The fact that self-advocates often require paid support workers is of core importance here. If people with a learning disability or autistic people do not get help to practice self-advocacy, then it is likely that many people will be excluded from collective forms of self-advocacy. It is also possible that lack of appropriate support will result in advocacy initiatives where only those self-advocates remain active who can find alternative forms of support (for example support paid for by themselves or support by friends and family). It is also possible that such informal or ad hoc support will mostly be available to those whose support needs are lower. For example, getting someone to walk with you to a meeting or help you send an email may be significantly easier than getting an assistant to help you 12 hours a day or to help you with augmentative communication aids that may require special expertise. It can be assumed that the lack of support is a serious barrier to all self-advocates but it is especially disabling to those with higher support needs.

Other barriers hindering self-advocacy

Self-advocacy may be deterred or even halted by other factors largely external to the disabled people's movement.

Such factors include the lack of legal capacity. Civil laws in many countries do not recognise disabled people having full rights to sign contracts, to make decisions such as refusing medical treatment, moving, voting, marrying or purchasing/selling something. In fact, guardianship is one of the greatest obstacles before disabled people's political participation (Priestley et al., 2016) which prevents them from exercising active citizenship (Waldschmidt et al., 2017). Although participants in this study were not asked about guardianship explicitly, several advocates referred to matters around legal capacity as a potential barrier to self-advocacy. For instance, several professional advocates raised doubts whether there is always a consensus between parents or guardians and their disabled family members – in some cases parents may advocate for issues that may run against the will of their disabled children.

Self-advocacy may also be difficult for those living in residential institutions. Several participants mentioned the lack of opportunities to self-advocate in social homes/hospitals, for example, because of a culture of fear. In fact, two self-advocates with a learning disability stated that they could only start self-advocacy after they moved out from a residential institution. This finding reasserts recent research that found that living in the community provides people with far more opportunities for exercising active citizenship (Šiška et al., 2017).

8.2.2 Facilitators to self-advocacy

Facilitator 1: The internet

The relevance of the internet was already found in previous literature presented in Chapter 2, but in this study it gained real salience only during data collection. Participants mentioned the internet in a myriad of contexts, often not even being aware that they highlighted an important facilitating factor. Self-advocates mentioned the internet as central in learning and getting information; others said they found their first peers online; some participants found help via websites; two participants self-diagnosed as autistic after extensive search on the world wide web. A series of advocacy practices are enhanced by the help of the internet: legal aid; online courses and lectures; peer support; self-help materials; online petitions; various opportunities offered by social media all contribute to a myriad of connections self-advocates and their allies establish and maintain.

The internet can also help self-advocates mitigate some of the adverse effects of barriers listed above. For instance, the internet offers a low-cost alternative to some offline activities,

192

such as when people do not have to pay for travel to meet in person. The internet also makes it possible to work in various ad hoc and long-term collectives without needing to establish an organisation. The internet may even help to tackle some of the problem arising from a lack of support: those who cannot attend meetings without a support worker can still 'Skype in' to join.

On the other hand, the internet also has its limitations. For example, participants with a learning disability used it with less confidence during recruitment in this study or did not use it at all. Not all advocacy practices can be enhanced or replaced with the opportunities offered by the internet and it is likely that many self-advocates find the internet less helpful or inaccessible. However, the internet has already helped self-advocates and their movement and it seems that its relevance is getting even stronger in today's mediatised society (Couldry, 2012). In fact, there is evidence that the internet can meaningfully help current disability advocacy through providing a number of opportunities for advocates to speak up and challenge disabling neoliberal policies, often even outside formal disability organisations (Pearson & Trevisan, 2015; Trevisan, 2016).

Facilitator 2: Human rights

The development of rights-based legislation has long been a tool for disability advocacy (Degener, 2000; García-Iriarte et al., 2015; Hurst, 1999; Vanhala, 2010). The CRPD itself is a result of nearly two decades of disability advocacy (Kanter, 2014). Since the adoption of the CRPD in 2007 (UN General Assembly, 2007), and other human rights legislation such as national anti-discrimination laws in Europe since the 1990s (Vanhala, 2015), much of disability advocacy uses the language and concept of human rights. Disabled legal scholar and chairperson of the UN Committee on the Rights of Persons with Disabilities Theresia Degener stated that '*disability has been reclassified as a human rights issue*' (Degener, 2000) and she put forward the 'human rights model' of disability (Degener, 2014; Degener, 2016). The CRPD is the *new big idea* of the international disability movement.

However, this study found that self-advocates and advocates have a rather limited knowledge about human rights and the CRPD, and most members of the learning disability and autism advocacy movement think human rights have not made a meaningful impact on their lives (Petri et al., 2017). In fact, participants in this study had a very limited awareness of human rights and the CRPD, despite the committed (self-)advocacy they did. Nevertheless, it would be a mistake to dismiss human rights mechanisms as entirely irrelevant here. Although palpable change was not seen by participants in this study, but

193

change is happening internationally on a macro level. For example, a number of European countries, including Austria, Hungary, Croatia, Czech Republic, Ireland, and Latvia have changed their legal capacity legislation recently (Turnpenny, Petri, Finn, Beadle-Brown, & Nyman, 2018). Although the new legal capacity laws are still being criticised by DPOs for not being progressive enough, the changes undeniably happened after extensive human rights lobby by DPOs and recommendations by the United Nations. Furthermore, several Central and Eastern European countries are implementing deinstitutionalisation strategies following extensive human rights lobby by DPOs and international organisations (Mladenov & Petri, under review; Petri & Kozma, 2017; Turnpenny et al., 2018). Currently, thousands of disabled people are leaving residential institutions across the region which will probably give them more opportunities to find self-advocacy collectives and speak up for their rights. Human rights may be a facilitator of self-advocacy if the human rights-lobby can remove some of the barriers mentioned before: deinstitutionalisation and progressive legal capacity laws are two examples where CRPD-driven changes have already contributed to (some) progress.

The recent publication of General Comment 7. by the UN Committee on the Rights of Persons with Disabilities may further initiate change and debate in the disability movement. The General Comment is part of the quasi-jurisprudence of the CRPD and it provides interpretation of the definition of 'disabled people's organisations' and 'self-advocacy organisations' (CRPD Committee, 2018). Notably, a group of international autistic self-advocates (Autistic Minority International, 2018) as well as international DPOs (controlled by parents and professionals) have been closely following the work on General Comment 7., bringing the work of the UN Committee on the Rights of Persons with Disabilities even closer to the disabled people's movement.

Facilitator 3: Community

All self-advocates in this study – similarly to almost all parent participants – stated that they found it empowering to be among their peers. Belonging to communities allowed them to continuously learn about the world and themselves. There was also a nearly unanimous opinion that self-advocacy itself (similarly to advocacy) is, in fact, a collective endeavour; even if individuals choose or are forced to self-advocate alone, they 'do it for everyone else'.

It is the assertion of this study that the community – finding a community, being in the community, working with others etc. – is one of the strongest facilitators of contemporary self-advocacy. By connecting people communities can get stronger, and members can receive information and support from communities. Importantly, such communities do not

194

have to be for 'self-advocates only'. Parents and other allies may valuably contribute to advocacy initiatives and they can also be part of support networks that help people to exercise advocacy. In the following, closing section of this study, the salience of communities and the Community of Practice approach will be appraised with potential implications for further research on self-advocacy.

8.3   COMMUNITIES OF PRACTICE AND SELF-ADVOCACY – A NEW OPPORTUNITY

It was one of the core findings of this study that the learning disability and autism advocacy movement may be similar to a Community of Practice (or is composed of Communities of Practices). This was suggested, because members of the movement are driven by a mutual interest, they have a shared set of practices, and, most importantly, they are a community – a group of people who engage '*in joint activities and discussions, help each other and share information*' (Wenger-Trayner & Wenger-Trayner, 2011, p. 2). Although Communities of Practice (CoP) were already briefly mentioned in Chapter 4, it is useful to take a closer look at the concept to appraise its relevance in the future of self-advocacy.

CoP is a concept developed by cognitive anthropologist Jean Lave and theorist Etienne Wenger in the 1990s (Wenger, 1999). Originally, the concept was applied to learning through apprenticeship in the entrepreneurial context, though it later gained broader relevance in a number of disciplines including social services (Bradshaw & Goldbart, 2013), mental health (Mancini & Miner, 2013), community psychology (Lawthom, 2011) and services for autistic people (Hooper, 2009). One of the core features of CoPs was that they allow their members to share knowledge and learn from one another – exactly what this study found to be a core feature of both self-advocacy (and parent-advocacy).

CoPs are distinct from organisations or teams in that they do not rely on set organisational rules and are far less hierarchical than organisations (Wenger, 1999; Wenger et al., 2002). Importantly, CoPs are more than just a network of people who know each other or live in each other's geographical proximity. Instead, CoPs develop and exist because its members engage in collective practices that contribute to the creation of new knowledge (Wenger, 1999, p. 6-7). According to the original concept, all CoPs share certain key features (Wenger, 1999):

- they build on the 'mutual engagement' of their members (through patterns of interaction and various activities in the community);
- they have a 'shared repertoire' (concepts, routines, techniques, jargon, symbols etc.);

- 'joint enterprise' (a unifying goal or common aim that the community tries to achieve).

When the concept of CoP was applied to disability activism in Britain by Rebecca Lawthom, it was found that CoPs can create spaces where activist from diverse backgrounds can share and create knowledge and participate in joint activities (Lawthom, 2012).

It is the assertion of this study that CoPs offer a new lens to look at self-advocacy. There are multiple reasons why CoPs and their cultivation within the disability movement may meaningfully contribute to the fuller participation of self-advocates. What follows is a number of considerations about CoPs in the context of the future of self-advocacy. The list takes inspiration from previous literature on CoP (Wenger & Snyder, 2000; Wenger et al., 2002), theoretical applications of the concept to disability activism (Lawthom, 2012) and, importantly, data collected in this project.

8.3.1 Benefits of a Community of Practice approach in self-advocacy

Based on findings of this study it is proposed that a CoP approach would bring a number of innovations that may benefit self-advocates, their allies and the whole of the disability movement. Although the study found that self-advocates are grossly marginalised in the disability movement today, and their exclusion is perpetuated and exacerbated by organisational practices and the uneven distribution of resources, for some ills of this situation the CoP approach can offer remedies[31].

8.3.1.1 CoPs support open dialogue between members

This study was launched because previous studies suggested, and a number of self-advocates claimed that the disability movement maintains practices that may exclude or marginalise people with a learning disability or autistic people. This study verified that the participation of self-advocates within DPOs was often on the level of tokenism. For example, self-advocates may be informed about decisions taken about them but they are not always

---

[31] Notably, although this study looked at self-advocates' position within the movement, but several participants mentioned that it is not only autistic people or people with a learning disability who are marginalised. Many parents and indeed many professionals may equally feel that they have little control over DPOs, charities or other advocacy entities that speak for communities. Parents may be locked out of advocacy merely because they cannot afford to engage with advocacy for economic reasons – poverty impacts the lives of millions, disabled and non-disabled people as well. Therefore, a CoP approach proposed here would potentially benefit everyone who wishes to join collective advocacy – self-advocates, parent-advocates and allies.

expected to confirm whether they agree with decisions. Self-advocates may also be 'consulted' before decision-making, but there is no clear and transparent process after consultations that shows how their views were considered. These practices constitute exclusionary policies that do not build on dialogue between those inside and those outside structures such as organisations or governing bodies of organisations.

CoPs, by their nature, build on sharing knowledge whereby members are invited to share their ideas if they want to. CoPs offer flexibility and space for sharing ideas and for maintaining dialogue among members. CoPs also offer more transparency to members because activities are shared and not restricted to an 'elite' who make decisions for others.

As presented earlier, it is possible that CoPs are already part of the disability movement and many autistic self-advocates are already members and beneficiaries of a CoP approach (even if autistic communities have not labelled their working method 'CoP'). At the same time, not only self-advocates but parents and many professionals are also members of such communities, in fact, it is possible that many of them share communities with self-advocates without consciously being aware of it. When asked about online advocacy and social media, several parents and professional stated in both countries that they have 'heard about' or 'follow' autistic communities. Parents also talked about parents' collectives on social media and other non-formalised forms of collectives such as local parents' groups. By further cultivating such communities dialogue could be initiated between groups of advocates. Opportunities and spaces for mutual learning and collective advocacy could be opened up, for example by consciously building on CoPs instead of expecting people to either join or establish formal organisations.

8.3.1.2   CoPs support new ways of learning

Much has been said about the relevance of knowledge in Disability Studies – the disabled people's movement and Disability Studies have aimed at creating emancipatory knowledge from the 1970s on (Barnes, 1998). CoPs are not revolutionary in this sense. What is new, lies at the heart of the CoP concept: a new way of engagement between members of communities. Instead of relying on set roles where some people give information while others are recipients of knowledge, CoPs build on shared knowledge that is created and constantly redefined through shared practices (Wenger, 1999).

Learning in a CoP has enormous potentials as it allows for implicit learning by sharing practices. One self-advocate may attend a training to learn new skills to speak up, but as we

saw in Chapter 4 self-advocacy practices go well beyond merely speaking up and learning can happen in other ways as well. Therefore, such training courses have necessarily limited effect. Training courses to gain new skills or technical (for example legal) knowledge may be indispensable for self-advocacy, but attention must be paid to tacit knowledge. Shared spaces of knowledge and collective practices are as much part of learning as are formal education. For example, when people attend street demonstrations the rules are rarely explicit and seldom taught at trainings. People may have vague awareness of certain rules (for example they may know that physical violence is against the law) but they may not know what to expect the first time they go to a demonstration, how to prepare etc. It is mostly through shared practices that they can learn – by doing it together with others – how to prepare a banner (to make it visible, large enough, what to write on it), when to arrive at a demonstration (not to be late, find a place in the crowd), how to chant (and what to chant) and so on.[32] Many of these bits of knowledge seem rather mundane but in fact, they belong to the repertoire of an activist just as much as the knowledge of certain civil rights. And then, during demonstrations new practices are being developed as unexpected things happen through the joint engagement of participants, for example when they create new, snappy slogans. This example can be replicated in other contexts: CoPs can support learning by allowing and encouraging people to do things together and constantly further develop existing knowledge through practice. For example, the concept (including its philosophy, practical applications, its jargon etc.) of neurodiversity may be *learned and exercised* through CoPs. Using Wenger's concept (1999), shared repertoires can be spread across communities that can also constantly shape and develop it as different people join (or leave) CoPs.

8.3.1.3 CoPs can help to avoid siloed views

Wenger notes (2002, p. 14-15) that CoPs allow the integration of multiple types of values, for example by connecting '*local pockets of expertise and isolated professionals'* or by '*linking unconnected activities and initiatives addressing similar knowledge domain'*. In the context of self-advocacy, one could argue that a myriad of different such pockets of expertise may exist that could find roads to each other through a CoP approach. Whilst formal organisations usually build on their paid teams or hired experts (or in the case of some charities and DPOs: on formal membership), CoPs offer the inclusion of seemingly distant

---

[32] Here, Lave and Wenger warn readers to think beyond the notion of 'learning in situ' or 'learning by doing'. (Wenger & Lave, 2001, p. 34-37) They shift from the notion of 'situated learning' (that is a transitory notion that bridges between cognitive processes and social practices) to the concept of 'legitimate peripheral participation', to be presented later.

knowledge. CoPs do not require that members share the same disciplinary background and may potentially involve members from very different backgrounds as the work on a certain issue progresses. Multidisciplinary approaches have long been valued in a broad range of services and it can be argued that CoPs have the potential to integrate different types of knowledge when members share a common goal.

8.3.1.4   CoPs cherish flexibility

In Chapter 7, several participants stated that the reason why self-advocates avoid disability organisations is that formal organisations are seen to maintain rigid structures. Many self-advocates try to avoid hierarchic structures where rules have been created (and are maintained) without their influence. Several participants stated that they had only limited time to engage with self-advocacy and they preferred to work as freelance or independent self-advocates because organisational work is akin to a 'full time' job. Participants may see advocacy organisations similar to a room: you are either inside or outside the room and if you are inside you have to accept certain rules. Compared to this model, CoPs offer flexibility to their members: there is no formal membership and there are various levels of involvement people can choose from. In fact, CoP encourages different levels of participation and the concept accepts '*legitimate peripheral participation'* (Wenger & Lave, 2001).

Legitimate peripheral participation allows people to be present and join mutual learning and do common practices while accepting that not every member wishes to participate on the same level. While membership in formal organisations or a job at a charity involves binding rules for membership/work, it also restricts participation for others: those who are 'in the room' should follow rules, and those who are 'outside' have very limited or no right to be present. CoPs allow much more flexible participation. The importance of this in the context of disability activism is described by Lawthom (2012):

> *Legitimate peripheral participation occurs when presence is allowed, and therefore members can peripherally participate in order to learn. A disabled individual may join an online network around disability and 'lurk' in the early stages without formally contributing. As times goes on, the 'lurking' permits her/him to understand the debates being aired, see her/his opinions differently, see how conflict is handled, and see how individuals respond to outbursts. Gradually, the legitimate peripheral participation afforded allows her/him a window in a community she/he had not previously experienced*. (Lawthom, 2012, p. 238)

199

Indeed, the above example by Lawthom presents a new way of engagement largely unknown to formal organisations operating in today's disability movement. Importantly, levels of participation (see Figure 8.1) are also flexible in CoPs (Wenger & Lave, 2001). For example, members can shift from peripheral to active participation in case they become motivated – the boundaries are fluid and even people outside the community can become involved (Wenger et al., 2002). In fact, instead of 'forcing participation', CoPs may 'build benches' for those not wishing to be involved fully, in a peripheral position. 'Semiprivate interaction' can encourage such fluid interaction, for example through private discussions between active and core members and those on the periphery. Leaders of CoPs can also take on limited leadership roles, as they have time for a project or have a certain interest to commit to the achievement of a specific target (Wenger et al., 2002). Flexibility and legitimate peripheral participation may make CoPs more attractive to some self-advocates than formal organisations.
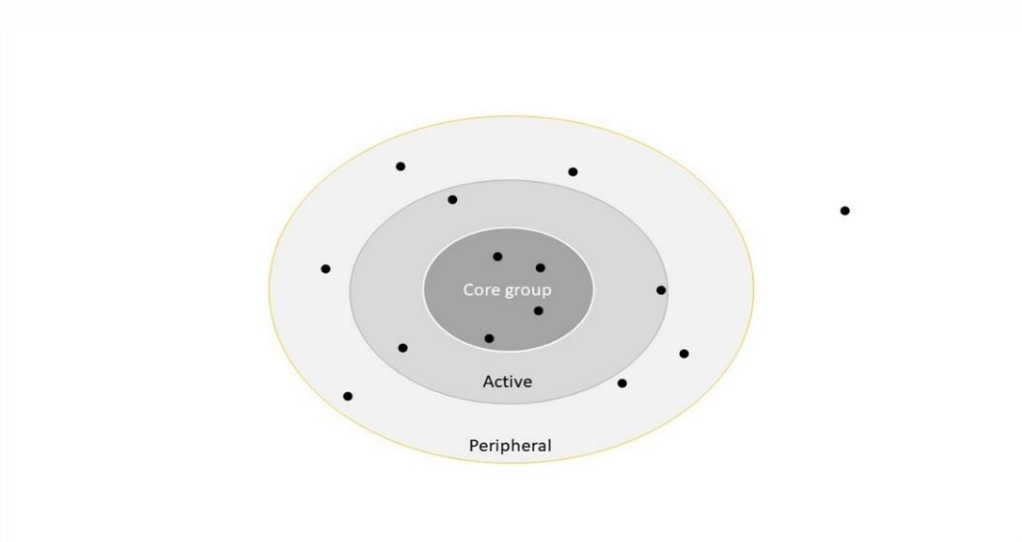
Figure 8.1 Degrees of community participation (adapted from Wenger, McDermott & Snyder, 2002)

Different degrees of community participation – theorised by Wenger and his colleagues – are already practised by many self-advocates in the autistic community. Participants in this study (including many parents and professionals) often talked about following the work of advocacy collectives (for Wenger: 'sitting on benches') or occasionally attending meetings with others, or even sometimes initiating actions they carried out with ad hoc groups of

people. Many of these activities were not organised by organisations but by a set of people who worked (practiced self-advocacy) together.[33]

The CoP approach is already being recognised by academics and activists alike. For example, participatory research initiatives have used it to build communities and develop new knowledge through the meaningful involvement of their members (Fletcher-Watson et al., 2018). Therefore, CoPs may show an example to advocacy collectives that strive to challenge the status quo in the disability movement. It can be assumed that by documenting how current CoPs work and by making information about the CoP approach available within the movement can contribute to the broader recognition of the model. As new CoPs will develop, experience and know-how can inspire communities to cultivate their CoPs. Importantly, although Wenger highlights that CoPs cannot be established 'from scratch', but they can be cultivated in a number of ways (Wenger et al., 2002). For example, CoPs can facilitate dialogue between inside and outside perspectives, they can develop both public and community spaces and initiate regular activities to engage members of the community.

8.3.2 Limitations of a CoP approach

Despite all their benefits, CoPs also have limitations in facilitating autistic and learning disability self-advocacy – some barriers asserted in this study may not be successfully tackled by a CoP-approach.

For example, it is unlikely that CoPs alone can challenge the financial and political dominance of DPOs and charities within the disability movement. Structures of power and organisational traditions are likely to be stronger than the challenge CoPs may bring into the field. Notably, DPOs are also recognised entities by governments and international organisations such as the UN, in fact, their roles are 'codified' in the CRPD and subsequent national implementation policies of the CRPD. It is likely that governments and the UN will

---

[33] During the write-up of this report, the researcher became involved in a group that can be the beginning of one CoP, formed by a group of people, mostly autistic self-advocates in Hungary. The community regularly discussed various issues in a closed social media group. Members shared articles, videos, engaged in debates, talked about their own life experiences and planned advocacy actions together. Membership was not set in this community, and members were free to add new members. There were different levels of participation: core members who initiated meetings, members who regularly contributed to debates and also members who only followed conversations. The group started working on advocacy initiatives and started developing project proposals for funding. The online groups also met few times, although some members stated they preferred online communication.

continue to favour formalised, 'representative' organisations as opposed to more fluid forms of collective work such as CoPs.

CoPs may also be unable to challenge the financial barriers found to be salient in this study. Although some CoPs may be able to operate by relying on the Internet, physical meetings will likely to be necessary for some types of work, and many activities will still require financial resources. Even members of the 'core group' of a CoP may need remuneration for their work and other expenses will also need to be covered (meeting room, travel costs, doing research, publishing or producing materials etc.). Members of CoPs will still need support, sometimes extensive support that needs to be paid for. Indeed, CoPs and their funding is a challenge that needs to be solved as the model itself does not offer readily available solutions.

Finally, although the CoP approach may be more easily applied to autistic self-advocacy, but for people with a learning disability, the approach will probably bring its challenges. It is unlikely that CoPs can or should replace traditional self-advocacy groups where members demand regular meetings with peers, they rely on the support given by assistants and activities offered to them. Indeed, it is likely that not everyone is interested in working in a CoP approach. In this study, self-advocates with a learning disability were almost unanimously content with their self-advocacy groups managed and supported by others. The Pathways Model in Chapter 5 also found that such 'old' self-advocacy groups are needed and valued by their members. It remains unclear how such traditional self-advocacy groups can benefit from a CoP approach and further research could confirm whether some groups have already – perhaps unintentionally – work as CoPs.

8.4 CLOSING REMARKS

One of the objectives of this research was to contribute to our knowledge on contemporary self-advocacy. This study offered several findings that constitute new knowledge about autistic and learning disability (self-)advocacy: the suggested new practice-based analysis (Chapter 4), the Pathways Model (Chapter 5), findings on the salience of economic barriers to self-advocacy (Chapter 6) and self-advocates' tokenistic involvement in DPOs (Chapter 7) all constitute bits of 'new knowledge'. It is the researcher's hope that these findings will inform practice and will also contribute to new kinds of conversations between members of the disability movement.

However, it is possible that there are facilitators and barriers of self-advocacy that have remained unidentified. This report focused on some systemic issues within the disability movement (such as the distribution of resources or the DPOs operate), but there may be other factors outside the findings of the present study.

For example, although many participants made references to the impairment of self-advocates in the context of various issues asked during interviews, this report avoided seeing impairment as a core explanatory factor. Instead, the study focused on broader, societal factors within and without the movement. This decision was taken for two reasons. First, looking at impairment would have taken this research project into a very different direction with the risk of completing a deficit-centred study. Second, the literature review in Chapter 2 demonstrated that there have already been several studies that looked at self-advocates' individual lives and how they self-advocate with appropriate support. However, the aim of this study was different: it looked at the disability movement and explored barriers in the societal or macro level of self-advocacy.

Furthermore, although this study built on data coming from British and Hungarian advocates and self-advocates, national contexts were not used in the thesis as background information. This approach was taken because the project aimed to explore factors present in both countries with the hope that similarities across countries may make it possible to assert some general conclusions about other national disability movements, or indeed about the 'international disability movement'.

However, it is possible that there are factors in national contexts that are only relevant to self-advocates working in that specific country. Indeed, factors that disable or facilitate self-advocacy may sometimes be specific to one country or even one region. These factors can be national laws and policies, or conventions followed by core organisations that dominate a national context. This study did not offer an analysis for such country-specific factors. However, findings are still relevant to both the British and Hungarian situation. In other words, although not all factors specific to British or Hungarian self-advocacy were identified, but all the factors identified are relevant to both British and Hungarian contexts.

It must be acknowledged that any factors that help or hinder self-advocates will always be local and specific to a national or even regional context self-advocates live in. Therefore, generalisations based on this research must be careful: it is likely that findings of this study are relevant to self-advocacy in many other countries, but differences will always be found.

Several findings of this study also call for further research. For example, the use of internet, including its benefits and limitations for self-advocates would be a fertile area for future investigations. The two groups (autistic people and people with a learning disability) may be markedly different in their relationship to the opportunities offered by the internet. However, future research could investigate the use of internet both by autistic communities and by communities of people with learning disabilities, to explore the potential of mediatised and networked self-advocacy. Filippo Trevisan's (2016) recent book may be a good example on how internet-based studies can contribute to our understanding of disability activism.

Furthermore, although this study employed an inclusive approach and data was collected from many participants who worked outside formalised advocacy organisation, it is possible that many disabled people self-advocate in more mundane ways. Indeed, it must be recognised that many autistic people or people with a learning disability may self-advocate in their everyday lives in myriad different ways, not mentioned in this study, far away from DPOs, charities and other organisations. Further research on these less-professionalised forms of self-advocacy should explore their role in people's lives or their relationship to formal (self-)advocacy. A practice-theory based approach, employed in Chapter 4 may be useful to investigate this potentially fertile area for enquiries.

Social movement studies could also inspire new research on disability advocacy because very little is known about how people with cognitive differences participate in contemporary social or political movements. This study showed powerfully that autistic people and people with a learning disability are politically conscious citizens. They become self-advocates because they see injustice. They join advocacy because they want to save their peers from experiencing discrimination. They practice activism intertwined with their everyday routine activities, even if they do not 'speak up'. Self-advocacy is there, in their everyday lives. There can be no doubt that learning disability and autism self-advocacy is a form of political activism where people stand up against oppressive practices. This is why it may be surprising that social movement studies have ignored disabled people. We know very little about how people with a cognitive difference join political movements. We do not know whether direct actions, political organisations or grassroots political groups are equipped with the knowledge that is required to reach out and include them into political movements. This research demonstrated convincingly that self-advocates' lack of visibility in the disability movement is largely due to systemic barriers present in the movement (and not in their

cognitive differences). It is possible that similarly disabling barriers are present in every level of contemporary social movements. Future research should look at how political parties, social movement groups, activist collectives, social protests etc. include or exclude people with a learning disability or autistic people.

***

This research provided an analysis of the position of autistic people and people with a learning disability within the contemporary disability movement. The study showed that self-advocates – despite all the support they get from their allies such as parents and professionals – are still second-class members in the disability movement. It is time that academia takes this fact seriously and looks at exclusionary practices in the disability movement (including in human rights mechanisms) more closely. The disability movement has never been fully united and internal fractions and hierarchies persist despite the emancipatory foundations the movement was built on. The academic community owe a debt to those silenced in the disability movement. Fortunately, there are signs of change. The researcher is convinced that future investigations will be led by those coming from this silenced minority and that the present study can contribute to their work.

REFERENCES

Albert, Á. (2016, 18 July). A legtöbb furcsaságukról nincs tudomásuk [Most of their obscurities are not even known]. *Abcúg,* Retrieved 3 December 2018 from https://abcug.hu/a-legtobb-furcsasagukrol-nincs-tudomasuk/

Americans with disabilities act, Pub. L. No. 101-336, 104 Stat. 328 (1990).

Amieletunk. (2013). *Bercse László munkatársunk OFT kinevezése* [Our colleague Laszlo Bercse has been elected to the OFT] (http://amieletunk.efoesz.hu/bercse-laszlo-oft-kinevezese/). Budapest: EFOESZ.

Anderson, S., & Bigby, C. (2015). Self-Advocacy as a means to positive identities for people with intellectual disability: 'We just help them, be them really'. *Journal of Applied Research in Intellectual Disabilities,* 30(1), 109-120*.*

ANED. (2018). Employment - article 27 of the CRPD. Retrieved 3 December 2018 from https://www.disability-europe.net/theme/employment. Academic Network of European Disability Experts.

Arnstein, S. R. (1969). A ladder of citizen participation. *Journal of the American Institute of Planners, 35*(4), 216-224.

ASAN. (2018). Autistic Self Advocacy Network. Retrieved 7 December from http://autisticadvocacy.org/

Asperger+. (2016). Fórum autisták es Asperger-szindrómások számára [Forum for autistic people and people with Asperger Syndrome]. Retrieved 9 December 2018 from https://aspergerplusz.wordpress.com/

Aspis, S. (2002). Self-advocacy: Vested interests and misunderstandings. *British Journal of Learning Disabilities, 30*(1), 3-7.

Aspis, S. (1997). Self-advocacy for people with learning difficulties: Does it have a future? *Disability and Society, 12*(4), 647-654. Retrieved 5 December 2018 from http://search.proquest.com/docview/839079282?accountid=7408

Atkinson, D. (1998). Reclaiming our past - empowerment through oral history and personal stories. In L. Ward (Ed.), *Innovations in advocacy and empowerment for people with intellectual disabilities* (pp. 115-126) London: Lisieux Hall Publishers.

Atkinson, D. (1999). *Advocacy: A review.* Brighton: Pavilion for the Joseph Rowntree Foundation.

Atkinson, D. (2004). Research and empowerment: Involving people with learning difficulties in oral and life history research. *Disability & Society, 19*(7), 691-702.

Atkinson, D. (2010). Narratives and people with learning disabilities. *In. Grant, G., Ramcharan, P. & Flynn, M. (Eds.), Learning Disability: A Life Cycle Approach to Valuing People,* 7-27.

Atkinson, D., Cooper, M., & Ferris, G. (2006). Advocacy as resistance – Speaking up as a way of fighting back. In. Mitchell D., Traustadottir R., Chapman R., Townson L., Ingham N. & Ledger S. (Eds). *Exploring Experiences of Advocacy by People with Learning Disabilities: Testimonies of Resistance. London: Jessica Kingsley,* pp. 13-19.

Atkinson, D., McCarthy, M., Walmsley, J., Cooper, M., & Ferris, G. (Eds.). (1999). *Good times, bad times: Women with learning difficulties telling their stories*. Kidderminster: BILD.

Autism Europe. (2013). 10. International Autism Europe Congress, Budapest. Retrieved 9 December 2018 from http://www.autismeurope.org/wp-content/uploads/2017/08/autism-europe-congress-2013-programme.pdf

Autism Europe. (2016). *Pietro Cirrincione, Autism-Europe's first self-advocate vice-president*. Brussels: Autism Europe. Retrieved 9 December 2018 from http://www.autismeurope.org/blog/2016/01/19/326/

Autistic Minority International. (2018). At UN conferences - 97 autings and counting. Retrieved 9 December 2018 from http://www.autisticminority.org/united-nations-conferences/

Azzopardi, A. (2000). A case study of a parents' self-advocacy group in Malta. *Disability & Society, 15*(7), 1065-1072. doi:10.1080/713662021

Baár, M. (2015). Informal networks, international developments and the founding of the first interest-representing associations of disabled people in Hungary in the late socialist period (1970s–1980s). *Journal of Social History and the History of Social Movements, 53*, 39-62. doi:http://dx.doi.org/10.13154/mts.53.2015.39-62

Bagatell, N. (2007). Orchestrating voices: Autism, identity and the power of discourse. *Disability & Society, 22*(4), 413-426.

Bagatell, N. (2010). From cure to community: Transforming notions of autism. *Ethos, 38*(1), 33-55.

Baker, D. L. (2011). *The politics of neurodiversity: Why public policy matters*. London: Lynne Rienner Publishers Boulder.

Balazs, E., Csillag, S., Kocsis, M., Orosz, A., Udvarhelyi, T., & Vágó, I. (2015). *Akciókutatás a magyar autizmus ellátórendszer fejlesztéséért* [Action research for the improvement of services for autistic people in Hungary]. Budapest: FSZK Nonprofit Kft.

Balázs, Z., & Petri, G. (2010). Az autizmussal élőket segítő magyarországi civil ellátórendszer kialakulása. In V. Bognár (Ed.), *Láthatatlanok. autista emberek a társadalomban* [Organisations helping people with autism in Hungary and their role in the development of policies and services] (pp. 36-77). Budapest: SCOLAR.

Bantekas, I., & Oette, L. (2013). *International human rights law and practice.* Cambridge: Cambridge University Press.

Barbour, R. (2008). *Doing focus groups*. London: Sage.

Barnes, C. (1998). The social model of disability: A sociological phenomenon ignored by sociologists? In T. Shakespeare (Ed.), *The disability reader: Social science perspectives* (pp. 65-78) London: Bloomsbury Academic.

Barnes, C. (2012). Understanding the social model of disability. past, present, future. In N. Watson, A. Roulstone & C. Thomas (Eds.), *Routledge handbook of disability studies* (pp. 12-29). New York: Routledge.

Barnes, C., & Mercer, G. (2010). *Exploring disability.* Cambridge: Polity.

Barnes, C., & Oliver, M. (1995). Disability rights: Rhetoric and reality in the UK. *Disability & Society, 10*(1), 111-116. doi:10.1080/09687599550023769

Barnes, C., & Sheldon, A. (2010). Disability, politics and poverty in a majority world context. *Disability & Society, 25*(7), 771-782. doi:10.1080/09687599.2010.520889

Barnett, J., & Hammond, S. (1999). Representing disability in charity promotions. *Journal of Community & Applied Social Psychology, 9*(4), 309-314.

Bartlett, P. (2012). The United Nations Convention on the Rights of Persons with Disabilities and mental health law. *The Modern Law Review, 75*(5), 752-778.

Beart, S. (2005). 'I won't think of meself as a learning disability. But I have': Social identity and self-advocacy. *British Journal of Learning Disabilities, 33*(3), 128-131.

Beckett, A. E. (2006). Understanding social movements: Theorising the disability movement in conditions of late modernity. *The Sociological Review, 54*(4), 734-752.

Benford, P., & Standen, P. (2009). The internet: A comfortable communication medium for people with Asperger Syndrome (AS) and high functioning autism (HFA)? *Journal of Assistive Technologies, 3*(2), 44-53. doi:10.1108/17549450200900015

Beresford, P. (1996). Poverty and disabled people: Challenging dominant debates and policies. *Disability & Society, 11*(4), 553-568. doi:10.1080/09687599627598

Beresford, P. (2012). Psychiatric system survivors. An emerging movement. In N. Watson, A. Roulstone & C. Thomas (Eds.), *Routledge handbook of disability studies* (pp. 151-164). New York: Routledge.

Bertilsdotter, H., Brownlow, C., & O'Dell, L. (2015). 'An association for All'—Notions of the meaning of autistic self-advocacy politics within a parent-dominated autistic movement. *CASP Journal of Community & Applied Social Psychology, 25*(3), 219-231.

Bérubé, M. (2018). *The secret life of stories: From don quixote to harry potter, how understanding intellectual disability transforms the way we read*. New York: New York University Press.

Bickenbach, J. E., Chatterji, S., Badley, E. M., & Üstün, T. B. (1999). Models of disablement, universalism and the international classification of impairments, disabilities and handicaps. *Social Science & Medicine, 48*(9), 1173-1187.

Biernacki, P., & Waldorf, D. (1981). Snowball sampling: Problems and techniques of chain referral sampling. *Sociological Methods & Research, 10*(2), 141-163.

Bigby, C. (2015). *Self-advocacy and inclusion: A summary of the study 'what can be learned from speaking up over the years'.* La Trobe University.

Birtha, M. (2014a). The role of self-advocacy groups in challenging traditionally exclusive patterns and negative attitudes towards persons with ID in the community. Paper presented at the 2014 IASSIDD Conference. *Journal of Applied Research in Intellectual Disabilities, , 27*(4) 349-349.

Birtha, M. (2014b). *Making the new space created in the UN CRPD real: Ensuring the voice and meaningful participation of the disability movement in policy-making and national monitoring.* (Unpublished PhD). Centre for Disability Law and Policy, School of Law, National University of Ireland, Galway.

Blackmore, T., & Hodgkins, S. L. (2012). Discourses of disabled peoples' organisations: Foucault, Bourdieu and future perspectives. In: D. Goodley, B. Hughes and L. Davis (eds.), *Disability and Social Theory: New developments and directions* (pp.70-88) London: Palgrave Macmillan.

Bloustien, G., & Wood, D. (2016). Visualising disability and activism in second life. *Current Sociology, 64*(1), 101-121. doi:10.1177/0011392115596025

Blume, H. (1997, 30 June). Autistics are communicating in cyberspace. *New York Times.* Retrieved 9 December 2018 from
https://partners.nytimes.com/library/cyber/techcol/063097techcol.html

Booth, T., & Booth, W. (1996). Sounds of silence: Narrative research with inarticulate subjects. *Disability & Society, 11*(1), 55-70. doi:10.1080/09687599650023326

Boxall, K. (2002). Individual and social models of disability and the experiences of people with learning difficulties. In: D. G. Race (Ed.) *Learning disability—a social approach* (pp.209-226). London: Routledge.

Bradshaw, J., & Goldbart, J. (2013). Staff views of the importance of relationships for knowledge development: Is training by specialists a waste of money? *Journal of Applied Research in Intellectual Disabilities, 26*(4), 284-298. doi:10.1111/jar.12020

Braithwaite, J., & Mont, D. (2009). Disability and poverty: A survey of world bank poverty assessments and implications. *ALTER-European Journal of Disability Research/Revue Européenne De Recherche Sur Le Handicap, 3*(3), 219-232.

Brashers, D. E., Haas, S. M., & Neidig, J. L. (1999). The patient self-advocacy scale: Measuring patient involvement in health care decision-making interactions. *Health Communication, 11*(2), 97-121.

Brashers, D. E., Haas, S. M., Neidig, J. L., & Rintamaki, L. S. (2002). Social activism, self-advocacy, and coping with HIV illness. *Journal of Social and Personal Relationships, 19*(1), 113-133.

Bräuchler, B., & Postill, J. (Eds.). (2010). *Theorising media and practice*. Oxford and New York: Berghahn Books.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101.

Broderick, A. A., & Ne'eman, A. (2008). Autism as metaphor: Narrative and counter-narrative. *International Journal of Inclusive Education, 12*(5-6), 459-476.

Brownlow, C., & O'Dell, L. (2006). Constructing an autistic identity: AS voices online. *Mental Retardation, 44*(5), 315-321.

Buchanan, I., & Walmsley, J. (2006). Self-advocacy in historical perspective. *British Journal of Learning Disabilities, 34*(3), 133-138. doi:10.1111/j.1468-3156.2006.00410.x

Butler, J. (2011). *Gender trouble: Feminism and the subversion of identity.* London: Routledge.

Bylov, F. (2006). Patterns of culture & power after 'The great release': The history of movements of subculture & empowerment among Danish people with learning difficulties. *British Journal of Learning Disabilities, 34*(3), 139-145.

Caldwell, J. (2011). Disability identity of leaders in the self-advocacy movement. *Intellectual and Developmental Disabilities, 49*(5), 315-326. doi:10.1352/1934-9556-49.5.315

Callus, A. (2014). From 'for' to 'of': A typology of Maltese disability organisations. *Disability & Society, 29*(1), 1-15. doi:10.1080/09687599.2013.776487

Campbell, F. (2009). *Contours of ableism: The production of disability and abledness*. Basingstoke: Palgrave Macmillan.

Campbell, J., & Oliver, M. (1996). Disability politics. *London: Routledge.*

Chamak, B., & Bonniau, B. (2013). Autism and social movements in France: A comparative perspective. In Davidson, J. & Orsini, M. (eds). *Worlds of Autism: Across the Spectrum of Neurological Difference* (pp. 239-257). University of Minnesota Press.

Chamak, B. (2008). Autism and social movements: French parents' associations and international autistic individuals' organisations. *Sociology of Health & Illness, 30*(1), 76-96. doi:10.1111/j.1467-9566.2007.01053.x

Chapman, M., Bannister, S., Davies, J., Fleming, S., Graham, C., Mcmaster, A., & Whittell, B. (2012). Speaking up about advocacy: Findings from a partnership research project. *British Journal of Learning Disabilities, 40*(1), 71-80.

Chapman, R. (2005). *The role of the self-advocacy support-worker in UK People First groups.* (Unpublished PhD). Open University,

Chappell, A. L. (1998). Still out in the cold: People with learning difficulties and the social model of disability. In T. Shakespeare (Ed.), *The disability reader: Social sciences perspectives* (pp. 211-220) London: Continuum.

210

Chappell, A. L., Goodley, D., & Lawthom, R. (2001). Making connections: The relevance of the social model of disability for people with learning difficulties. *British Journal of Learning Disabilities, 29*(2), 45-50.

Charmaz, K., & Belgrave, L. L. (2007). Grounded theory. In Ritzer, G. (Ed.) *The Blackwell Encyclopedia of Sociology* (pp. 2023-2027), Oxford: Blackwell Publishing.

Clark, D., Fry, T., & Rodgers, J. (1998). Woman to woman: Setting up and running a health advocacy group for women. In L. Ward (Ed.), *Innovations in advocacy and empowerment for people with intellectual disabilities* (pp. 129-140) London: Lisieux Hall Publications.

Clarke, R., Camilleri, K., & Goding, L. (2015). What's in it for me? the meaning of involvement in a self-advocacy group for six people with intellectual disabilities. *Journal of Intellectual Disabilities : JOID, 19*(3), 230-250. doi:10.1177/1744629515571646 [doi]

Collins, H. M. (2001). What is tacit knowledge. In T. Schatzki, K. Cetina Knorr & E. von Savigny (Eds.), *The practice turn in contemporary theory* (pp. 107-119) Routledge London.

Corker, M. (1998). Disability discourse in a postmodern world. In T. Shakespeare (Ed.), *The disability reader: Social science perspectives* (pp. 221-233) London: Bloomsbury Academic.

Couldry, N. (2012). *Media, society, world: Social theory and digital media practice*. Cambridge: Polity.

Crawley, B. (1988). *The growing voice: A survey of self-advocacy groups in adult training centres and hospitals in Great Britain*. London: Department of Psychology, Inst. of Psychiatry.

Cronin, A. (2013). Focus groups. In N. Gilbert (Ed.), *Researching social life* (pp. 226-244). London: Sage.

CRPD. (2018). *General comment no. 7. on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the convention*. Geneva: United Nations Committee on the Rights of Persons with Disabilities.

Davidson, J. (2008). Autistic culture online: Virtual communication and cultural expression on the spectrum. *Social & Cultural Geography, 9*(7), 791-806. doi:10.1080/14649360802382586

Davidson, J., & Henderson, V. L. (2010). 'Coming out' on the spectrum: Autism, identity and disclosure. *Social & Cultural Geography, 11*(2), 155-170. doi:10.1080/14649360903525240

Davis, L. J. (2010). Constructing normalcy. In Davis, L.J. (Ed.) *The disability studies reader* (pp. 3-20). New York: Routledge.

Dawson, M. (2003). No autistics allowed. Autism Society Canada speaks for itself - an open letter. Retrieved 9 December 2018 from http://www.sentex.net/~nexus23/naa_js.html

Degener, T. (2000). International disability law - A new legal subject on the rise: The interregional experts' meeting in Hong Kong, December 13-17, 1999. *Berkeley International Journal of Law, 18*(1), 180-195.

211

Degener, T. (2014). A human rights model for disability. In P. Blanck, & E. Flynn (Eds.), *Routledge handbook of disability law and human rights* (pp. 31-50). London and New York: Routledge.

Degener, T. (2016). Disability in a human rights context. *Laws, 5*(3), 35.

Dekker, M. (1999). On our own terms: Emerging autistic culture. Retrieved 1 December 2018 from http://www.autscape.org/2015/programme/handouts/Autistic-Culture-07-Oct-1999.pdf

Della Porta, D., & Diani, M. (2009). *Social movements: An introduction, second edition.* Oxford: Blackwell Publishing.

Denzin, N. K., & Lincoln, Y. S. (1994). *Handbook of qualitative research.* London: Sage Publications.

Disability discrimination act (1995). Retrieved 9 December 2018 from http://www.legislation.gov.uk/ukpga/1995/50/contents

Disabled People Against Cuts. (2016). Retrieved 9 December 2018 from http://dpac.uk.net/

Docherty, A., Harkness, E., Eardley, M., Townson, L., & Chapman, R. (2006). What they Want– Yes, but what we Want–Bugger us! In Mitchell, D., Traustadottir, R., Chapman, R., Townson, L., Ingham, N., and Ledger, S. (eds) *Exploring Experiences of Advocacy by People with Learning Disabilities: Testimonies of Resistance,* (pp. 100-108), London: Jessica Kingsley Publishers.

Docherty, D., Hughes, R., Phillips, P., Corbett, D., Regan, B., Barber, A., Izzidien, S. (2005). This is what we think. In Goodley, D. & van Hove, G. (eds.) *Another Disability Studies Reader, (*pp. 29-49). Antwerpen: Garant Uitgivers.

Douglas, H., & Harpur, P. (2016). Intellectual disabilities, domestic violence and legal engagement. *Disability & Society, 31*(3), 305-321. doi:10.1080/09687599.2016.1167673

Douzinas, C. (2013a). Seven theses on human rights: (3) neoliberal capitalism & voluntary imperialism. *Critical Legal Thinking, Thesis 3*, 19 January 2017. Retrieved 9 December 2018 from http://criticallegalthinking.com/2013/05/23/seven-theses-on-human-rights-3-neoliberal-capitalism-voluntary-imperialism/.

Douzinas, C. (2013b). Seven theses on human rights: Depoliticization. *Critical Legal Thinking, Thesis 5*, 19 January 2017. Retrieved 9 December from http://criticallegalthinking.com/2013/05/31/seven-theses-on-human-rights-5-depoliticization/

Downer, J., & Ferns, P. (1998). Self-advocacy by black people with learning difficulties. In Ward, L. (Ed.), *Innovations in advocacy and empowerment for people with intellectual disabilities* (pp. 141-150) London: Lisieux Hall Publications.

Dowse, L. (2001). Contesting practices, challenging codes: Self advocacy, disability politics and the social model. *Disability & Society, 16*(1), 123-141.

Dowse, L. (2009). 'Some people are never going to be able to do that'. challenges for people with intellectual disability in the 21st century. *Disability & Society, 24*(5), 571-584.

212

Duguid, P. (2005). "The art of knowing": Social and tacit dimensions of knowledge and the limits of the community of practice. *The Information Society, 21*(2), 109-118.

Durdella, N. (2017). *Qualitative dissertation methodology: A guide for research design and methods* London: SAGE Publications.

Dybwad, G., & Bersani, H. A. (1996). *New voices: Self-advocacy by people with disabilities.* Cambridge, Mass: Brookline Books.

Earl, J., & Kimport, K. (2011). *Digitally enabled social change: Activism in the internet age.* Mit Press.

ÉFOÉSZ. (2016a). Retrieved 9 December 2018 from http://efoesz.hu/kiadvanyok/

ÉFOÉSZ. (2016b). Mi, nők - szívességkommandó [Us, women - 'combating with love']. Retrieved from https://www.facebook.com/minokprojekt/home

Ellis, K., & Goggin, G. (2015). *Disability and the media.* London: Palgrave Macmillan.

Ellis, K., Goggin, G., Huntsinger, J., & Senft, T. (2014). Disability and social media. In Hunsinger, T. & Senft, T. (eds), *The Social Media Handbook (pp.* 126-143). London and New York: Routledge.

EPSA. (2017). European Platform of Self-Advocates. Retrieved 1 December 2018 from http://self-advocacy.eu/

European Disability Forum. (2016). Retrieved 1 December 2018 from http://www.edf-feph.org/

European Disability Forum. (2017). Building an inclusive disability movement for the future. Retrieved 1 December 2018 from http://www.edf-feph.org/newsroom/news/building-inclusive-disability-movement-future

European Disability Forum. (2018). About us. Brussels: EDF.

Feinstein, A. (2010). *A history of autism: Conversations with the pioneers.* London: John Wiley & Sons.

Fielding, N., & Thomas, H. (2013). Qualitative interviewing. In N. Gilbert (Ed.), *Researching social life* (pp. 245-265). London: Sage.

Finkelstein, V. (1993). Disability: A social challenge or an administrative responsibility. In J. SWAIN, V. FINKELSTEIN, S. FRENCH & M. Oliver (Eds.), *Disabling barriers, enabling environments* (pp. 32-43) Sage, London.

Finkelstein, V. (1998). Emancipating disability studies. *Shakespeare, T. (Ed.), The Disability Reader: Social Science Perspectives,* (pp. 28-49). London: Continuum.

Finlay, M., & Lyons, E. (1998). Social identity and people with learning difficulties: Implications for self-advocacy groups. *Disability & Society, 13*(1), 37-51. doi:10.1080/09687599826902

Fitzgerald, J. (1998). It's never too late: Empowerment for older people with learning difficulties. In L. Ward (Ed.), *Innovations in advocacy and empowerment for people with intellectual disabilities* (pp. 151--160) London: Lisieux Hall Publications.

Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., Pellicano, E. (2018). Making the future together: Shaping autism research through meaningful participation. *Autism,* doi:10.1177/1362361318786721

Flynn, E. (2013). Making human rights meaningful for people with disabilities: Advocacy, access to justice and equality before the law. *The International Journal of Human Rights, 17*(4), 491-510.

Flynn, M., & Ward, L. (1991). "We can change the future" self and citizen advocacy". In Segal, S. & Varma, V. (eds)*, Prospects for People with Learning Difficulties* (pp. 101-114). London: David Fulton Publishers.

Forbat, L., & Atkinson, D. (2005). Advocacy in practice: The troubled position of advocates in adult services. *British Journal of Social Work, 35*(3), 321-335.

Foucault, M. (1977). *Discipline and punishment.* London: Allen Lane.

French, S. (1993). Disability, impairment or something in between? In J. SWAIN, V. FINKELSTEIN, S. FRENCH & M. OLIVER (Eds.), *Disabling barriers - enabling environment* (pp. 17-25) Open University Press.

Frith, U. (2008). *Autism: A very short introduction.* Oxford University Press.

Fundamental Rights Agency. (2013). *Legal capacity of persons with intellectual disabilities and persons with mental health problems.* (). Vienna: European Union Agency for Fundamental Rights. Retrieved 11 June 2018 from http://fra.europa.eu/sites/default/files/legal-capacity-intellectual-disabilities-mental-health-problems.pdf.

Gander, K. (2015, 21 May). Gavin Harding: UK's first mayor with a learning disability appointed in selby. *Independent,* Retrieved 2 December 2018 from https://www.independent.co.uk/news/uk/home-news/gavin-harding-uks-first-mayor-with-a-learning-disability-appointed-in-selby-10268437.html

Garcia Iriarte, E. (2016). Models of disability. In E. Garcia Iriarte, R. McConkey & R. Gilligan (Eds.), *Disability and human rights - global perspectives* (pp. 10-32) Macmillan Education - Palgrave.

García-Iriarte, E., McConkey, R., & Gilligan, R. (2015). *Disability and human rights: Global perspectives* Palgrave Macmillan.

García-Iriarte, E., O'Brien, P., McConkey, R., Wolfe, M., & O'Doherty, S. (2014). Identifying the key concerns of Irish persons with intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 27*(6), 564-575. doi:10.1111/jar.12099

Gerland, G. (2003). *A real person: Life on the outside.* Souvenir Press.

Giddens, A. (1979). Agency, structure. In. Giddens, A. *Central problems in social theory* (pp. 49-95). London: Palgrave.

Giddens, A. (1984). *The constitution of society: Outline of the theory of structuration*. University of California Press.

Giddens, A. (1989). *Sociology.* Cambridge: Polity Press.

Gilbert, N. (2008). *Researching social life.* London: Sage.

Gillman, M., Swain, J., & Heyman, B. (1997). Life history or 'Case' history: The objectification of people with learning difficulties through the tyranny of professional discourses. *Disability & Society, 12*(5), 675-694. doi:10.1080/09687599726985

Gombos, G., Kovacs, M., Szollosine, F. E., & Tapolczay, G. (2010). *Fogyatékos személyek jogai vagy fogyatékos jogok? -- A magyar civil caucus párhuzamos jelentése az ENSZ egyezményről.* [Disability rights or disabled rights? Paralel report on the CRPD by the Hungarian disability caucus]. Budapest: SINOSZ - MDAC - FESZT. Retreived 9 December 2018 from http://mek.oszk.hu/13000/13044/13044.pdf

Gonzalez, R. G., & Cox, A. (2013). (2013). Our turn? An evaluation of the turn to the practice based approach in information science. Paper presented at the *Informationswissenschaft Zwischen Virtueller Infrastruktur Und Materiellen Lebenswelten. Tagungsband Des 13. Internationalen Symposiums Für Informationswissenschaft (ISI 2013), Potsdam, 19.—22. März 2013,* Potsdam. 63-80.

Goodley, D., Downer, J., Burke, P., Kershaw, J., Page, L., & Souza, A. (2000). Collecting the life stories of self-advocates: Crossing the boundary between the researcher and the researched*. In Brigham, L. (Ed.) Crossing Boundaries: Change and Continuity in the History of Learning Disability* (pp. 159-175). BILD Publications.

Goodley, D. (2001). 'Learning difficulties', the social model of disability and impairment: Challenging epistemologies. *Disability & Society, 16*(2), 207-231.

Goodley, D. (2011). *Disability studies: An interdisciplinary introduction.* London: Sage Publications.

Goodley, D. (2014). *Dis/ability studies: Theorising disablism and ableism.* London: Routledge.

Goodley, D. (2000). *Self-advocacy in the lives of people with learning difficulties : The politics of resilience*. Buckingham: Open University Press.

Goodley, D., Hughes, B., & Davis, L. (2012). *Disability and social theory: New developments and directions*. London: Palgrave Macmillan.

Goodley, D., & Moore, M. (2000). Doing disability research: Activist lives and the academy. *Disability & Society, 15*(6), 861-882.

Goodley, D., & Ramcharan, P. (2010). Advocacy, campaigning and people with learning. In G. Grant, P. Ramcharan, M. Flynn & M. Richardson (Eds.), *Learning disability. A life cycle approach.* (pp. 87-100) McGraw-Hill Education (UK).

Goodley, D. (1996). Tales of hidden lives: A critical examination of life history research with people who have learning difficulties. *Disability & Society, 11*(3), 333-348.

Goodley, D. (2004). The place of people with 'learning difficulties' in disability studies and research: Introduction to this special issue. *British Journal of Learning Disabilities, 32*(2), 49-51. doi:10.1111/j.1468-3156.2004.00279.x

Goodley, D. (2005). Empowerment, self-advocacy and resilience. *Journal of Intellectual Disabilities, 9*(4), 333-343. doi:10.1177/1744629505059267

Goodley, D. (2013). Dis/entangling critical disability studies. *Disability & Society, 28*(5), 631-644. doi:10.1080/09687599.2012.717884

Goodley, D., Lawthom, R., & Runswick-Cole, K. (2014). Dis/ability and austerity: Beyond work and slow death. *Disability & Society, 29*(6), 980-984. doi:10.1080/09687599.2014.920125

Grandin, T. (2009). *Thinking in pictures.* London: Bloomsbury Publishing.

Gray, B., & Jackson, R. (2002). Introduction: Advocacy and learning disability. In B. Gray, & R. Jackson (Eds.), *Advocacy and learning disability* (pp. 7-23). London: Jessica Kingsley.

Grech, S. (2009). Disability, poverty and development: Critical reflections on the majority world debate. *Disability & Society, 24*(6), 771-784.

Grove, N. (2015). Finding the sparkle: Storytelling in the lives of people with learning disabilities. *Tizard Learning Disability Review, 20*(1) doi:10.1108/TLDR-05-2014-0015

Hacking, I. (2009). How we have been learning to talk about autism: A role for stories. *Metaphilosophy, 40*(3-4), 499-516.

Hagan, T. L., & Donovan, H. S. (2013). Self-advocacy and cancer: A concept analysis. *Journal of Advanced Nursing, 69*(10), 2348-2359.

Hamilton, C., & Atkinson, D. (2009). 'A story to tell': Learning from the life-stories of older people with intellectual disabilities in Ireland. *British Journal of Learning Disabilities, 37*(4), 316-322.

Harpur, P. (2010). Time to be heard: How advocates can use the convention on the rights of persons with disabilities to drive change. *Valparaiso University Law Review, 45(3)*, 1271-1296.

Harpur, P. (2012). Embracing the new disability rights paradigm: The importance of the convention on the rights of persons with disabilities. *Disability & Society, 27*(1), 1-14.

Haselfux, P. (1995). *A félelem nem úr - autista vagyok?* [Fear cannot win - Am I autistic?]. Százhalombatta: EFO.

216

Hasler, F. (1993). Developments in the disabled people's movement. *Disabling Barriers, Enabling Environments.* London: Sage.

Hauben, H., Coucheir, M., Spooren, J., McAnaney, D., & Delfosse, C. (2012). *Assessing the impact of European governments' austerity plans on the rights of people with disabilities.* Brussels: European Consortium of Foundations on Human Rights and Disability - Bernhard Brunhes International BPI Group. Retrieved 9 December 2018 from http://www.enil.eu/wp-content/uploads/2012/12/Austerity-European-Report_FINAL.pdf

Heath, J. (2015). "Methodological individualism". In E. N. Zalta (Ed.), *The stanford encyclopedia of philosophy (spring 2015 edition)*. Retrieved 30 October 2018 from https://plato.stanford.edu/archives/spr2015/entries/methodological-individualism/

Hegedűs, L., Kurunczi, M., Szepessyné Judik, D., Pajor, E., & Könczei, G. (2009). *A fogyatékosságügy hazai és nemzetközi története* [The history of the disability field in Hungary and internationally]. Budapest: ELTE.

Henderson, A. (2011). A young autistic man, magna carta, human rights and unlawful detention. Retrieved from https://ukhumanrightsblog.com/2011/06/16/a-young-autistic-man-magna-carta-human-rights-and-unlawful-detention/

Hess, R. S., Molina, A. M., & Kozleski, E. B. (2006). Until somebody hears me: Parent voice and advocacy in special educational decision making. *British Journal of Special Education, 33*(3), 148-157.

Hild, A. (2017). *"I fight for every person with a disability to be respected and treated with dignity"*. Brussels: Inclusion Europe.

Holland, D. (2008). The current status of disability activism and non-governmental organizations in post-communist Europe: Preliminary findings based on reports from the field. *Disability & Society, 23*(6), 543-555.

Holland, D. (2001). *Identity and agency in cultural worlds.* Harvard University Press.

Hooper, B. (2009). *Cultivating communities of practice in autism*. Richmond: CoPA Conference, Virginia Commonwealth University.

Hoy, J., Cautrels, D., & Goodley, D. (2006). The life of a group and a personal story. *Mitchell, D., Traustadottir, R., Chapman, R., Townson, L., Ingham, N., and Ledger, S. (eds) Exploring Experiences of Advocacy by People with Learning Disabilities: Testimonies of Resistance (pp.* 108-117). London: Jessica Kingsley Publishers

Hreinsdóttir, E. E., Stefánsdóttir, G., Lewthwaite, A., Ledger, S., & Shufflebotham, L. (2006). Is my story so different from yours? Comparing life stories, experiences of institutionalization and self-advocacy in England and Iceland. *British Journal of Learning Disabilities, 34*(3), 157-166.

Hsieh, H., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research, 15*(9), 1277-1288.

217

Hungarian Civil Liberties Union. (2016). MONDO card game. Retrieved 11 December 2018 from http://szuloi.tasz.hu/english/

Hungarian Disability Caucus. (2010). *'Disability rights or disabling rights?'.* Budapest: SINOSZ - FESZT. Retrieved from http://mdac.org/en/resources/disability-rights-or-disabling-rights-crpd-alternative-report

Hungarian Parliament. (1998). *1998. évi XXVI. törvény a fogyatékos személyek jogairól és esélyegyenlőségük biztosításáról [Law on the rights and equal opportunities of disabled people, 1998/26]*

Hunt, P. (1998). A critical condition (1966). In Shakespeare, T. (Ed.) *The Disability Reader: Social Science Perspectives (pp.* 7-19). London: Continuum.

Hurst, R. (1999). Disabled people's organisations and development: Strategies for change. In E. Stone (Ed.), *Disability and development. Learning from action and research on disability in the majority world* (pp. 25-35). Leeds: Disability Press.

Hurst, R. (2003). The international disability rights movement and the ICF. *Disability and Rehabilitation, 25*(11-12), 572-576.

Ignatieff, M. (2003). *Human rights as politics and idolatry.* Princeton University Press.

Inclusion Europe. (2016a). Disability convention (CRPD). Brussels: Inclusion Europe.

Inclusion Europe. (2016b). Inclusion international's global self-advocacy initiative. Retrieved 1 December 2018 from http://inclusion-europe.eu/?p=1672

Inclusion Europe, & Inclusion International. (2005). *Poverty and intellectual disability in Europe.* Brussels: Inclusion Europe. Retrieved 1 December 2018 from http://inclusion-europe.eu/wp-content/uploads/2015/03/SocInc_EUPovertyRreport.pdf

Inclusion International. (2016). Robert Martin elected to UN committee. Retrieved 8 December 2018 from http://inclusion-international.org/robert-martin-elected-un-committee/

Johnson, K. (2006). Taking a stand against the odds. In D. Mitchell, R. Traustadóttir, R. Chapman, L. Townson, N. Ingham & S. Ledger (Eds.), *Exploring experiences of advocacy by people with learning disabilities* (pp. 179-188.) London: Jessica Kingsley Publishers.

Kahn, R., & Kellner, D. (2004). New media and internet activism: From the 'battle of Seattle' to blogging. *New Media and Society, 6*(1), 87-95.

Kálmán, Z., & Könczei, G. (2002). *A taigetosztól az esélyegyenlőségig* [From the Taygetus to equal opportunities]. Budapest: Osiris.

Kanter, A. S. (2003). The globalization of disability rights law. *Syracuse Journal of International Law and Commerce, 30*, p. 241-263.

Kanter, A. S. (2014). *The development of disability rights under international law: From charity to human rights.* London: Routledge.

218

Kayess, R., & French, P. (2008). Out of darkness into light? Introducing the Convention on the Rights of Persons with Disabilities. *Human Rights Law Review,* doi:10.1093/hrlr/ngm044

Keck, M. E., & Sikkink, K. (1999). Transnational advocacy networks in international and regional politics. *International Social Science Journal, 51*(159), 89-101.

Kemény, P., Kondor, Z., & Tausz, K. (2014). Disability studies in hungary / studij hendikepa na madzarskem. *Socialno Delo, 53*(3-5), 147-162.

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2015). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism,* doi:10.1177/1362361315588200

Kevan, C., Morales, E. B. R., Constantinou, I. A., Bayonas, I., Ceonzo, J., Curtis, J., Dillmann, P. (2018). *Autism mothers speak out: Stories of advocacy and activism from around the world.* London: Jessica Kingsley Publishers.

Kitzinger, J. (1994). The methodology of focus groups: The importance of interaction between research participants. *Sociology of Health & Illness, 16*(1), 103-121. doi:10.1111/1467-9566.ep11347023

Knowles, T. (2014, March 14). Thousands of patients in care homes are drugged and locked up, say peers. *The Times, UK.*

Kowalski, R. M., & Fedina, C. (2011). Cyber bullying in ADHD and Asperger syndrome populations. *Research in Autism Spectrum Disorders, 5*(3), 1201-1208.

Lashley, K. (2016). Displaying autism. the thinking and images of *temple grandin* (2010). In B. Fraser (Ed.), *Cultures of representation. disability in world cinema context* (pp. 126-140) Columbia University Press.

Lawson, A. (2006). United Nations Convention on the Rights of Persons with Disabilities: New era or false dawn?. *Syracuse Journal of International Law & Commerce, 34*, 563.

Lawson, A., & Priestley, M. (2013). Potential, principle and pragmatism in concurrent multinational monitoring: Disability rights in the European Union. *The International Journal of Human Rights, 17*(7-8), 739-757.

Lawson, W. (2001). *Understanding and working with the spectrum of autism: An insider's view* London: Jessica Kingsley Publishers.

Lawthom, R. (2011). Developing learning communities: Using communities of practice within community psychology. *International Journal of Inclusive Education, 15*(1), 153-164.

Lawthom, R. (2012). Lave and Wenger, Communities of Practice and Disability Studies. In D. Goodley, B. Hughes & L. Davis (Eds.), *Disability and social theory. new developments and directions* (pp. 233-251). New York: Palgrave Macmillan.

Le Guide Social. (2018). *L'inclusion passe (aussi) par l'associatif*. Brussels: Le Guide Social.

Ledger, S., & Tilley, L. (2006). The history of self-advocacy for people with learning difficulties: International comparisons. *British Journal of Learning Disabilities, 34*(3), 129-130.

Llewellyn, P., & Northway, R. (2008). The views and experiences of people with intellectual disabilities concerning advocacy: A focus group study. *Journal of Intellectual Disabilities : JOID, 12*(3), 213-228. doi:10.1177/1744629508095726 [doi]

Lowery, A. (2016,). Alex lowery speaks about autism. Retrieved 8 December 2018 from http://www.alexlowery.co.uk/resources/blog/

Mack, T. (2005, 14 April). We'll do it our way. *The Guardian* Retrieved 1 December 2018 from https://www.theguardian.com/theguardian/2001/apr/14/weekend7.weekend10

Malinga, J., & Gumbo, T. (2016). Advocacy and lobbying: The road map from charity to human rights. In E. Garcia Iriarte, R. McConkey & R. Gilligan (Eds.), *Disability and human rights - global perspectives* (pp. 49-67) Palgrave - Macmillan Education.

Malli, M. A., Sams, L., Forrester-Jones, R., Murphy, G., & Henwood, M. (2018). Austerity and the lives of people with learning disabilities. A thematic synthesis of current literature. *Disability & Society, *, 1-24. doi:10.1080/09687599.2018.1497950

Mancini, M. A., & Miner, C. S. (2013). Learning and change in a community mental health setting. *Journal of Evidence-Based Social Work, 10*(5), 494-504. doi:10.1080/15433714.2012.760944

Marchant, R. (1998). Letting it take time. rights work with disabled children and young people. In L. Ward (Ed.), *Innovations in advocacy and empowerment* (pp. 183-198) London: Lisieux Hall Publishers.

Maslow, A. H. (1943). A theory of human motivation. *Psychological Review, 50*(4), 370.

Masschelein, A., & Van Goidsenhoven, L. (2016). Posting autism. Online self-representation strategies in Tistje, a Flemish blog on 'Living on the spectrum from the front row'. In K. Ellis, & M. Kent (Eds.), *Disability and social media: Global perspectives* (pp. 255-273). New York: Routledge.

McColl, M., & Boyce, W. (2003). Disability advocacy organizations: A descriptive framework. *Disability and Rehabilitation, 25*(8), 380-392. doi:10.1080/0963828021000058521

McGuire, A. (2012). Representing autism: A sociological examination of autism advocacy. *Atlantis: Critical Studies in Gender, Culture & Social Justice, 35*(2), 62-71.

McGuire, A. (2013). Buying time: The s/pace of advocacy and the cultural production of autism. *Canadian Journal of Disability Studies, 2*(3), 98-125.

McGuire, A. (2016). *War on autism: On the cultural logic of normative violence* University of Michigan Press.

McLeod, S. (2007). Maslow's hierarchy of needs – *Simply Psychology.* Retrieved 8 December 2018 from http://www. simplypsychology.org/maslow.html

McNally, J. (2005). *Advocacy and empowerment. self-advocacy groups for people with a learning disability.* (Unpublished PhD). London South Bank University,

Mcnally, S. (2003). A survey of self-advocacy groups for people with learning disabilities in an English region part II. *Journal of Learning Disabilities, 7*(3), 231-249.

McVilly, K. R., Stancliffe, R. J., Parmenter, T. R., & Burton-Smith, R. M. (2006). Self-advocates have the last say on friendship. *Disability & Society, 21*(7), 693-708.

Meekosha, H., & Shuttleworth, R. (2009). What's so 'critical' about critical disability studies? *Australian Journal of Human Rights, 15*(1), 47.

Meininger, H. P. (2010). Connecting stories: A narrative approach of social inclusion of persons with intellectual disability. *ALTER-European Journal of Disability Research/Revue Européenne De Recherche Sur Le Handicap, 4*(3), 190-202.

Mental Disability Advocacy Center. (2015). *Access to justice for children with mental disabilities. project summary report.* Budapest: MDAC. Retrieved 8 December 2018 from http://www.mdac.org/en/access-to-justice-for-children-country-report-summary

Meyers, S. (2014). Global civil society as megaphone or echo chamber?: Voice in the international disability rights movement. *International Journal of Politics, Culture, and Society, 27*(4), 459-476.

Meyers, S. (2016). NGO-ization and human rights law: The CRPD's civil society mandate. *Laws, 5*(2), 147-160. doi: 10.3390/laws5020021

Michels, R. (1962). *Political parties: A study of the oligarchical tendencies of modern democracy*. New York: Collier Books.

Miller, A., & Keys, C. (1996). Awareness, action, and collaboration: How the self-advocacy movement is empowering for persons with developmental disabilities. *Mental Retardation, 34*(5), 312-319.

Mills, G. (2013, 29 July). Spain's down syndrome councillor makes history. *The Local,* Retrieved 8 December 2018 from https://www.thelocal.es/20130729/spain-first-down-syndrome-councillor

Milton, D. (2010). *The identity of parent 'advocates' of autistic children: A discursive psychological examination of two in-depth interviews. Project report. (unpublished).* Milton Keynes: The Open University.

Milton, D. (2014). Autistic expertise: A critical reflection on the production of knowledge in autism studies. *Autism : The International Journal of Research and Practice, 18*(7), 794-802. doi:10.1177/1362361314525281 [doi]

Milton, D., Mills, R., & Pellicano, L. (2012). Ethics and autism: Where is the autistic voice? commentary on post et al. *Journal of Autism and Developmental Disorders, 44*(10), 2650-2651.

Mitchell, D., Traustadóttir, R., Chapman, R., Townson, L., Ingham, N., & Ledger, S. (2006). *Exploring experiences of advocacy by people with learning disabilities: Testimonies of resistance* Jessica Kingsley Publishers.

Mittler, P. (1996). 'Preparing for self-advocacy'. In B. Carpenter, C. Stevens, K. Bovair & R. Ashdown (Eds.), *Enabling access*. David Fulton Publishers.

Mittler, P. (2016). The UN convention on the rights of persons with disabilities: Implementing a paradigm shift. In E. Garcia Iriarte, R. McConkey & R. Gilligan (Eds.), *Disability and human rights - global perspectives.* (pp. 33-48) Palgrave.

Mladenov, T. (2015). From state socialist to neoliberal productivism: Disability policy and invalidation of disabled people in the postsocialist region. *Critical Sociology,* 43(7–8), 1109–1123. https://doi.org/10.1177/0896920515595843

Mladenov, T. (2016). *Critical theory and disability: A phenomenological approach*. New York and London: Bloomsbury.

Mladenov, T., & Petri, G. (under review). Critique of deinstitutionalisation in post-socialist Central and Eastern Europe.

Mocsonoky, A. (2018). *Autista a gyerekem. 13 személyes élettörténet küzdelemről és elfogadásról* [My child is autistic. 13 personal stories about struggles and acceptance]. Budapest: HVG konyvek.

Moody, L., Saunders, J., Leber, M., Wójcik-Augustyniak, M., Szajczyk, M., & Rebernik, N. (2017). An exploratory study of barriers to inclusion in the European workplace. *Disability and Rehabilitation, 39*(20), 2047-2054. doi:10.1080/09638288.2016.1217072

Moore, M., Beazley, S., & Maelzer, J. (1998). *Researching disability issues.* McGraw-Hill Education (UK).

Nagase, O. (2016). (2016). A conversation with the framers – panel discussion. . Paper presented at the *8th International Summer School on Disability Law. Bringing Rights Home - Civil Society Impacting Change,* NUI Galway, Ireland. Retrieved 8 December 2018 from https://www.youtube.com/playlist?list=PLvKS9kpe3SYP_qkvruWIUqzv5cWPeYfzM

Nash, K. (2015). *The political sociology of human rights.* Cambridge University Press.

Ne'eman, A. (2010). The future (and the past) of autism advocacy, or why the ASA's magazine, the advocate, wouldn't publish this piece. *Disability Studies Quarterly, 30*(1)

Newshub. (2016), Robert Martin's historic election to UN disabilities committee. *Newshub,* Retrieved 1 December 2018 from https://www.newshub.co.nz/home/health/2016/06/robert-martins-historic-election-to-un-disabilities-committee.html

Nind, M. (2006). Stereotyped behaviour: Resistance by people with profound learning difficulties. In D. Mitchell, R. Traustadóttir, R. Chapman, L. Townson, N. Ingham & S. Ledger (Eds.), *Exploring experiences of advocacy by people with learning disabilities. testimonies of resistance.* (pp. 202-211) London: Jessica Kinglsey.

222

O'Brien, J., Browning, R., & O'Brien, C. L. (1998). One day at a time: Changing a system to realize a dream.

O'Byrne, C., & Muldoon, O. T. (2018). The construction of intellectual disability by parents and teachers. *Disability & Society,* 1-23. doi:10.1080/09687599.2018.1509769

Oliver, M. (1990). *The politics of disablement*. London: Macmillan Education.

Oliver, M., & Barnes, C. (2012). *The new politics of disablement.* London: Palgrave Macmillan.

Oliver, M. (1997). The disability movement is a new social movement! *Community Development Journal, 32*(3), 244-251.

Oliver, M., & Barnes, C. (2006). Disability politics and the disability movement in Britain: Where did it all go wrong? *Greater Manchester Coalition of Disabled People,* August 2006.

Oravecz, L., & Fekete, V. G. (2016). Autista vagyok. [I am autistic] Retrieved 8 December 2018 from https://www.youtube.com/user/autistavagyok/featured

Oravecz, L., & Orosz, I. (2017). *Lizanka - Egy autista lány története a bezártságtól a teljes élet felé* [Lizanka - The story of an autistic girl from isolation towards a full life]. Budapest: HVG Könyvek.

Orsini, M., & Smith, M. (2010). Social movements, knowledge and public policy: The case of autism activism in Canada and the US. *Critical Policy Studies, 4*(1), 38-57. doi:10.1080/19460171003714989

Ortega, F. (2009). The cerebral subject and the challenge of neurodiversity. *BioSocieties, 4*(4), 425-445.

Ortega, F., Zorzanelli, R., & Rios, C. (2016). The biopolitics of autism in Brazil. In Runswick-Cole, K., Mallet, R. & Timimi, Sami (eds), *Re-Thinking Autism: Diagnosis, Identity and Equality* (pp. 67-86). London: Jessica Kingsley Publishers.

Owen, K. (2006). Restriction and resistance. In Mitchell, D., Traustadottir, R., Chapman, R., Townson, L., Ingham, N., and Ledger, S. (eds) *Exploring Experiences of Advocacy by People with Learning Disabilities: Testimonies of Resistance (pp. 20-27). London: Jessica Kingsley Publishers*.

Papp, G., Pál, J., & Keszi, R. (2014). Cooperation and exclusion: An explorative analysis of collaborative networks of Hungarian disability organizations. *Corvinus Journal of Sociology and Social Policy,* (1), 143-161.

PARC. (2018). The participatory autism research collective. Retrieved 8 December 2018 from https://participatoryautismresearch.wordpress.com/

Parsloe, S. M. (2015). Discourses of disability, narratives of community: Reclaiming an autistic identity online. *Journal of Applied Communication Research, 43*(3), 336-356. doi:10.1080/00909882.2015.1052829

Parsloe, S. M., & Holton, A. E. (2017). #Boycottautismspeaks: Communicating a counternarrative through cyberactivism and connective action. 1-18. *Information, Communication & Society,* , 1-18. doi:10.1080/1369118X.2017.1301514

Pearson, C., & Trevisan, F. (2015). Disability activism in the new media ecology: Campaigning strategies in the digital era. *Disability & Society, 30*(6), 924-940.

Pelka, F. (2012). *What we have done: An oral history of the disability rights movement.* University of Massachusetts Press.

Pellicano, E., Dinsmore, A., & Charman, T. (2014). Views on researcher-community engagement in autism research in the united kingdom: A mixed-methods study. *PloS One, 9*(10), e109946.

Pellicano, L. (2012). Who should speak for autistic people? London: Institute of Education. Retrieved 30 October 2018 from https://ioelondonblog.wordpress.com/2012/06/20/who-should-speak-for-autistic-people/

Petri, G. (2017). Children with learning disabilities and their participation in judicial procedures–what can disability advocacy offer? *Tizard Learning Disability Review, 22*(1), 10-15.

Petri, G., Beadle-Brown, J., & Bradshaw, J. (2017). "More honoured in the breach than in the Observance"—Self-advocacy and human rights. *Laws, 6*(4), 26.

Petri, G., & Kozma, Á. (2017). Közösségi életvitel és intézményi férőhelykiváltás Magyarországon. Kritikai elemzés. [Community living and deinstitutionalisation in Hungary. A critical analysis.] *Esély, 5*, 39-63.

Postill, J. (2011). Introduction: Theorising media and practice. In B. Brauchler, & J. Postill (Eds.), *Theorising media and practice* (pp. 1-27). Oxford and New York: Berghahn.

Priestley, M., Stickings, M., Loja, E., Grammenos, S., Lawson, A., Waddington, L., & Fridriksdottir, B. (2016). The political participation of disabled people in Europe: Rights, accessibility and activism. *Electoral Studies, 42*, 1-9.

Quinn, G. (2009). The united nations convention on the rights of persons with disabilities: Toward a new international politics of disability. *Texas Journal on Civil Liberties and Civil Rights, 15*(1), 33-52.

Quinn, G., Degener, T., & Bruce, A. (2002). *Human rights and disability: The current use and future potential of united nations human rights instruments in the context of disability.* Geneva: United Nations Publications.

Quinn, G., & Flynn, E. (2012). Transatlantic borrowings: The past and future of EU non-discrimination law and policy on the ground of disability. *American Journal of Comparative Law, 60*(1), 23-48.

Ramcharan, P., & Grant, G. (2001). Views and experiences of people with intellectual disabilities and their families. (1) the user perspective. *Journal of Applied Research in Intellectual Disabilities, 14*(4), 348-363. doi:10.1046/j.13602322.2001.00078.x

Reckwitz, A. (2002). Toward a theory of social practices: A development in culturalist theorizing. *European Journal of Social Theory, 5*(2), 243-263.

Rhiannon Salmons. (2016). Retrieved 8 December 2018 from https://www.youtube.com/channel/UCi4dWahPw2OEWroSsyH_L5Q

Roets, G., Adams, M., & Hove, G. V. (2006). Challenging the monologue about silent sterilization: Implications for self-advocacy. *British Journal of Learning Disabilities, 34*(3), 167-174.

Roets, G., & Goodley, D. (2008). Disability, citizenship and uncivilized society: The smooth and nomadic qualities of self-advocacy. *Disability Studies Quarterly, 28*(4)

Roth, I., Barson, C., Hoekstra, R., Pasco, G., & Whatson, T. (2010). *The autism spectrum in the 21st century: Exploring psychology, biology and practice.* Jessica Kingsley Publishers.

Runswick-Cole, K. (2014). 'Us' and 'them': The limits and possibilities of a 'politics of neurodiversity' in neoliberal times. *Disability & Society, 29*(7), 1117-1129. doi:10.1080/09687599.2014.910107

Runswick-Cole, K., & Goodley, D. (2015). Disability, austerity and cruel optimism in big society: Resistance and "The disability commons". *Canadian Journal of Disability Studies, 4*(2), 162-186.

Russell, G., & Norwich, B. (2012). Dilemmas, diagnosis and de-stigmatization: Parental perspectives on the diagnosis of autism spectrum disorders. *Clinical Child Psychology and Psychiatry, 17*(2), 229-245.

Russo, J. (2016). In dialogue with conventional narrative research in psychiatry and mental health. *Philosophy, Psychiatry, & Psychology, 23*(3), 215-228.

Ryan, S. (2016). (2016). What the fuckwhatery? Disability studies, activism and the continuing denial of the human. keynote presentation. Paper presented at the *Lancaster Disability Studies Conference, 6-8 September 2016,* Lancaster, UK. Retrieved 8 December 2018 from http://www.lancaster.ac.uk/fass/events/disabilityconference_archive/2016/index.htm

Ryan, S., & Cole, K. R. (2009). From advocate to activist? mapping the experiences of mothers of children on the autism spectrum. *Journal of Applied Research in Intellectual Disabilities, 22*(1), 43-53.

Sabatello, M., & Schulze, M. (2014). Introduction. In M. Sabatello, & M. Schulze (Eds.), *Human rights and disability advocacy* (pp. 1-13). Philadeplhia: University of Pennsylvania Press.

Sainsbury, C. (2009). *Martian in the playground: Understanding the schoolchild with Asperger's syndrome.* London: Sage.

Sanderson, H. (1998). A say in the future. involving people with profound and multiple disabilities in person centred planning. In L. Ward (Ed.), *Innovations in advocacy and empowerment* (pp. 161-182) London: Lisieux Hall Publishers.

Savage, P., Wilkinson, T., & Worth, C. (2006). My life, my choices. *In D. Mitchell, R. Traustadóttir, R. Chapman, L. Townson, N. Ingham & S. Ledger (Eds.), Exploring experiences of advocacy by people with learning disabilities. testimonies of resistance. (pp. 93-101) London: Jessica Kingsley.*

Schatzki, T. (1996). *Social practices: A Wittgensteinian approach to human activity and the social* Cambridge University Press.

Schatzki, T. (2001). Introduction: Practice theory. In T. Schatzki, K. Cetina Knorr & E. von Savigny (Eds.), *The practice turn in contemporary theory* (pp. 1-14). London: Routledge.

Semota. (2015). Asperger 2.0. Retrieved 5 September 2018 from http://livewithit.blog.hu/

Seth F., H. (2005). *Autizmussal önmagamba zárva*. Budapest: Kapocs Kiado.

Shakespeare, T. (1993). Disabled people's self-organisation: A new social movement? *Disability, Handicap & Society, 8*(3), 249-264.

Shakespeare, T. (1996). Disability, identity and difference. *Exploring the Divide,* , 94-113.

Shakespeare, T. (2006). *Disability rights and wrongs*. London: Routledge.

Shakespeare, T. (2010). The social model of disability. In L. J. Davis (Ed.), *The disability studies reader* (pp. 266-274) New York: Routledge.

Shakespeare, T. (2013). *Disability rights and wrongs revisited.* London: Routledge.

Shakespeare, T., & Watson, N. (2001). The social model of disability: An outdated ideology? *Exploring Theories and Expanding Methodologies: Where we are and Where we Need to Go,* (2), 9-28.

Shildrick, M. (2012). Critical disability studies: Rethinking the conventions for the age of postmodernity. In N. Watson, A. Roulstone & C. Thomas (Eds.), *Routledge handbook of critical disability studies* (pp. 30-41) Routledge.

Shore, S. M. (Ed.). (2004). *Ask and tell: Self-advocacy and disclosure for people on the autism spectrum*. Shawnee Mission: Autism Asperger Publishing Co.

Silberman, S. (2015). *Neurotribes: The legacy of autism and the future of neurodiversity*. New York: Penguin.

Simplican, S. C. (2015). *The capacity contract. Intellectual disability and the question of citizenship.* University of Minnesota Press.

Sinclair, J. (2005). Autism network international: The development of a community and its culture. Retrieved 8 December 2018 from http://www.autismnetworkinternational.org/History_of_ANI.html

Šiška, J., Beadle-Brown, J., Káňová, S., & Kittelsaa, A. (2017). Change and diversity in community living in Europe—The experiences of persons with disabilities. *Understanding the Lived Experiences of Persons with Disabilities in Nine Countries. Active Citizenship and Disability in Europe, 2*, 49-65.

Slater, J. (2012). Self-advocacy and socially just pedagogy. *Disability Studies Quarterly, 32*(1)

Slorach, R. (2014). Out of the shadows: Disability movements. *Critical and Radical Social Work, Volume 2*(Number 2), 159--174.

Slorach, R. (2015). *A very capitalist condition -- A history and politics of disability*. London: Bookmarks Publications.

Spassiani, N. A., & Friedman, C. (2014). Stigma: Barriers to culture and identity for people with intellectual disability. *Inclusion, 2*(4), 329-341. doi:10.1352/2326-6988-2.4.329

Spedding, F., Harkness, E., Townson, L., Docherty, A., & Chapman, R. (2002). The role of self-advocacy: Stories from a self-advocacy group through the experiences of its members. *In Gray, B. & Jackson, R. (eds) Advocacy and Learning Disability* (pp. 137-151). London: Jessica Kingsley Publishers.

Stalker, K. (2012). Theorising the position of people with learning difficulties within disability studies: Progress and pitfalls. In N. Watson, A. Roulstone & C. Thomas (Eds.), *Routledge handbook of disability studies* (pp. 122-135). New York: Routledge.

Stefánsdóttir, G., & Traustadóttir, R. (2006). Resilience and resistance in the life histories of three women with learning difficulties in Iceland. In D. Mitchell, R. Traustadóttir, R. Chapman, L. Townson, N. Ingham & S. Ledger (Eds.), *Exploring experiences of advocacy by people with learning disabilities. testimonies of resistance.* (pp. 54-67) London: Jessica Kingsley.

Stein, M. A. (2007). Disability human rights. *California Law Review*, *95(1),* 75-121.

Stein, M. A., & Lord, J. E. (2010). Monitoring the convention on the rights of persons with disabilities: Innovations, lost opportunities, and future potential. *Human Rights Quarterly, 32(1)*, 689-728.

Strnadová, I., & Walmsley, J. (2018). Peer-reviewed articles on inclusive research: Do co-researchers with intellectual disabilities have a voice? *Journal of Applied Research in Intellectual Disabilities, 31*(1), 132-141.

Sutcliffe, J., & Simons, K. (1993). *Self-advocacy and adults with learning difficulties.* Leicester: NIACE.

Thinking person's guide to autism. (2016). Retrieved 8 December 2018 from http://www.thinkingautismguide.com/

227

Thomas, C. (2002). Disability theory: Key ideas, issues and thinkers. In C. Barnes, M. Oliver & L. Barton (Eds.), *Disability studies today* (pp. 38-57). Cambridge: Polity Press.

Tideman, M., & Svensson, O. (2015). Young people with intellectual disability – the role of self-advocacy in a transformed Swedish welfare system. *International Journal of Qualitative Studies on Health and Well-Being, 10*:1 DOI: 10.3402/qhw.v10.25100

Tilley, L. (2006a). *Advocacy for people with learning difficulties: The role of two organisations.* (Unpublished PhD). New Hall College, Cambridge University.

Tilley, L. (2006b). Resistance in Mencap's history. In D. Mitchell, R. Traustadóttir, R. Chapman, L. Townson, N. Ingham & S. Ledger (Eds.), *Exploring experiences of advocacy by people with learning disabilities: Testimonies of resistance* (pp. 128-141) London: Jessica Kingsley Publishers.

Tilley, L. (2013). Management, leadership, and user control in self-advocacy: An English case study. *Mental Retardation, 51*(6), 470-481.

Traustadóttir, R. (2006). Learning about self-advocacy from life history: A case study from the United States. *British Journal of Learning Disabilities, 34*(3), 175-180. doi:10.1111/j.1468-3156.2006.00414.x

Trevisan, F. (2016). *Disability rights advocacy online: Voice, empowerment and global connectivity.* London: Routledge.

Tsuda, E., & Smith, J. (2004). Defining and organizing self-advocate centered groups: Implications of survey research on self-advocacy groups in Japan. *Disability & Society, 19*(6), 627-646. doi:10.1080/0968759042000252542

Turner, S. (1994). *The social theory of practices: Tradition, tacit knowledge, and presuppositions* University of Chicago Press.

Turnpenny, A., Petri, G., Finn, A., Beadle-Brown, J., & Nyman, M. (2018). Mapping and understanding exclusion: Institutional, coercive and community-based services and practices across Europe. Brussels: Mental Health Europe.

Convention on the rights of persons with disabilities : Resolution / adopted by the general assembly, (2007). Retrieved 8 December 2018 from http://www.un.org/disabilities/convention/conventionfull.shtml

Fundamental principles of disability, (1975). Retrieved 8 December 2018 from http://disability-studies.leeds.ac.uk/files/library/UPIAS-fundamental-principles.pdf

United Nations. (2018a). *States parties' reports*. Geneva: UN Office of the High Commissioner for Human Rights.

United Nations. (2018b). *States parties' reports and alternative reports*. Geneva: UN Office of the High Commissioner for Human Rights.

228

United Nations. (2018c). States parties' reports and paralel reports. Retrieved 8 December 2018 from https://www.ohchr.org/en/hrbodies/crpd/pages/spreports.aspx

United Nations Office of the High Commissioner on Human Rights. (2010). *Monitoring the convention on the rights of persons with disabilities. guidance for human rights monitors, professional training series No. 17.* New York - Geneva: United Nations. Retrieved 8 December 2018 from http://www.ohchr.org/Documents/Publications/Disabilities_training_17EN.pdf

United Nations Office of the High Commissioner on Human Rights. (2016). Retrieved 8 December 2018 from http://www.ohchr.org/EN/Issues/Pages/WhatareHumanRights.aspx

Vanhala, L. (2010). *Making rights a reality?: Disability rights activists and legal mobilization.* Cambridge University Press.

Vanhala, L. (2015). The diffusion of disability rights in Europe. *Human Rights Quarterly, 37*(4), 831-853.

Vehmas, S., & Watson, N. (2014). Moral wrongs, disadvantages, and disability: A critique of critical disability studies. *Disability & Society, 29*(4), 638-650. doi:10.1080/09687599.2013.831751

Volkmar, F. R., & Wiesner, L. A. (2009). *A practical guide to autism: What every parent, family member, and teacher needs to know.* Hoboken, New Jersey: John Wiley & Sons.

Waldschmidt, A., Tøssebro, J., Biggeri, M., Beadle-Brown, J., Hvinden, B., & Halvorsen, R. (2017). Changing opportunities for active citizenship: Understanding the lived experiences of persons with disabilities. *Understanding the lived experiences of persons with disabilities in nine countries* (pp. 1-16) Routledge.

Walmsley, J. (1993). 'Talking to top people': Some issues relating to the citizenship of people with learning difficulties. In J. Swain, V. Finkelstein, S. French & M. Oliver (eds.), *Disabling barriers - enabling environments* (pp. 257--266). Buckingham: The Open University.

Walmsley, J. (2002). Principles and types of advocacy. In *Gray B. & Jackson R. (eds.), Advocacy and Learning Disability.* (pp. 24-37). London: Jessica Kingsley Publishers.

Walmsley, J., & Mannan, H. (2009). Parents as co-researchers: A participatory action research initiative involving parents of people with intellectual disabilities in Ireland. *British Journal of Learning Disabilities, 37*(4), 271-276.

Walmsley, J., Tilley, L., Dumbleton, S., & Bardsley, J. (2017). The changing face of parent advocacy: A long view. *Disability & Society, 32*(9), 1366-1386.

Waltz, M. (2012). Images and narratives of autism within charity discourses. *Disability & Society, 27*(2), 219-233.

Waltz, M. (2013). *Autism: A social and medical history.* London: Palgrave Macmillan.

Waltz, M., Bosch, v. d. K., Ebben, H., Hal, v. L., & Schippers, A. (2015). Autism self-advocacy in the netherlands: Past, present and future. *Disability & Society, 30*(8), 1174-1191. doi:10.1080/09687599.2015.1090954

Ward, L. (1998). *Innovations in advocacy and empowerment for people with intellectual disabilities*. London: Lisieux Hall Publishers.

Ward, M. J., & Meyer, R. N. (1999). Self-determination for people with developmental disabilities and autism: Two self-advocates' perspectives. *Focus on Autism and Other Developmental Disabilities, 14*(3), 133-139. doi:10.1177/108835769901400302

Warde, A. (2005). Consumption and theories of practice. *Journal of Consumer Culture, 5*(2), 131-153.

Weber, M. (1978). *Economy and society: An outline of interpretive sociology*. Berkeley: University of California Press [1922] 1978)

Wehmeyer, M., Bersani, H., & Gagne, R. (2000). Riding the third wave: Self-determination and self-advocacy in the 21st century. *Focus on Autism and Other Developmental Disabilities, 15*(2), 106-115. doi:10.1177/108835760001500206

Wenger, E. (1999). *Communities of practice: Learning, meaning, and identity.* Cambridge University Press.

Wenger, E., & Lave, J. (2001). Legitimate peripheral participation in communities of practice. *Supporting lifelong learning* (pp. 121-136) Routledge.

Wenger, E., McDermott, R. A., & Snyder, W. (2002). *Cultivating communities of practice: A guide to managing knowledge.* Harvard Business Press.

Wenger, E., & Snyder, W. M. (2000). Communities of practice: The organizational frontier. *Harvard Business Review, 78*(1), 139-146.

Wenger-Trayner, E., & Wenger-Trayner, B. (2011). Communities of practice: A brief introduction. Retrieved 8 December 2018 from http://wenger-trayner.com/introduction-to-communities-of-practice/

Whittell, B., Ramcharan, P., & Cardiff, P. F. (1998). Self-advocacy - speaking up for ourselves and others. In L. Ward (Ed.), *Innovations in advocacy and empowerment for people with intellectual disabilties* (pp. 39-58) London: Lisieux Hall Publications.

Whittemore, R. D., Langness, L. L., & Koegel, P. (1986). The life history approach to mental retardation. In L. Langness & H. Levine (Ed.), Culture and Retardation. Kluwer: D. Reidel Publishing Company.

Williams, D. (1992). *Nobody nowhere.* Doubleday.

WNUSP (2018). International advocacy. Odense: World Network of Users and Survivors of Psychiatry. Retrieved 8 December from http://www.wnusp.net/index.php/international-advocacy.html

230

Žižek, S. (2005). Against human rights. *New Left Review* 34., July-August 2005. Retrieved 8 December from https://newleftreview.org/II/34/slavoj-zizek-against-human-rights

Appendices

Appendix 1. Arnstein's Ladder of Participation (English)

Ladder of citizen participation

Manipulation
Therapy
No power

Informing
Consultation
Placation
Degrees of tokenism

Partnership
Delegated power
Citizen control
Citizen control

Based on Arnstein 1969

Appendix 2. Arnstein's Ladder of Participation (Hungarian)

Az állampolgári részvétel létrája

Manipulláció

Terápia

Tájékoztatás

Konzultáció

Lekenyerezés

Partnerség

Delegált döntés

Állampolgári kontroll

Alávetettség

Jelképes részvétel (tokenizmus)

Állampolgári részvétel

Arnstein 1969 alapján

Appendix 3. Arnstein's Ladder of Participation, simplified (English)

The LADDER of PARTICIPATION

Therapy

Informing

Placation

Partnership

Citizen control

No power

Tokenism

Citizen participation

Arnstein 1969

Appendix 4. Arnstein's Ladder of Participation, simplified (Hungarian)

Az állampolgári részvétel létrája

Terápia
Tájékoztatás
Lekenyerezés
Partnerség
Állampolgári kontroll

Alávetettség

Jelképes részvétel

Állampolgári részvétel

Arnstein 1969 alapján

Appendix 5. Interview and focus group guide (English)

Themes for interviews and focus groups with self-advocates and advocates:

1. What is advocacy? What is self-advocacy?
2. Parents organisations and self-advocacy. What is parents' role in advocacy?
3. Role of the internet in doing (self-)advocacy
4. Who can become a successful self-advocate? (skills or competences; severity of impairment as factor)
5. Solo vs. group advocacy / self-advocacy?
6. Human rights – are they known and used as advocacy tools?
7. The Social Model of Disability – is it known, is it 'used'?
8. Money and financial resources. What is their significance in advocacy/self-advocacy?
9. Nothing about us without us – Participation model by Arnstein (1969). Involvement of self-advocates in DPOs or the movement as a whole.
10. Hierarchy within the disability movement (with other disability groups)
11. Knowledge about international practices ('knowledge transfer'). Do they know about advocacy abroad?
12. Intersectionality. Where are minorities in the self-advocacy/advocacy movement? (LGBTQI, religious or ethnic minorities etc.)

Témakörök interjúkhoz és fókuszcsoportokhoz

1. Mi az érdekvédelem? Mi az önérvényesítés?
2. Szülői szervezetek és szülők viszonya, szerepük önérvényesítésben?
3. Mi az internet jelentősége az érdekvédelemben?
4. Kiből válhat sikeres érdekvédő? (készségek és képességek; fogyatékosság súlyossága mint faktor)
5. Egyéni vagy csoportos érdekvédelem/önérvényesítés?
6. Emberi jogok – ismertek és használatosak az érdekvédelemben? (ENSZ Egyezmény is)
7. Fogyatékosság társadalmi modellje. Ismerik?
8. Pénz és anyagi erőforrások szerepe
9. Semmit rólunk, nékülünk – Részvétel szervezetek munkájában és a mozgalomban Arnstein (1969) alapján
10. Van hierarhia a fogyatékos emberek mozgalmában? (más fogyatékossági csoportokhoz viszonyítva autista és értelmi fogyatékos emberek helye)
11. Mit tudnak nemzetközi érdekvédelemről? Kapcsolatok. (tudástranszfer kérdése)
12. Interszekcionalitás. Cigány vagy LMBT vagy más kisebbségi (vallásos?) érdekvédők helye.

Appendix 7. Information sheet for interview participants (English)

Researcher: Gabor Petri
Email: gp249@kent.ac.uk, T: 01227 824770
Supervisor: Julie-Beadle Brown
Email: J.D.Beadle-Brown@kent.ac.uk, T:
01227 827763
Tizard Ethics Committee
Email: J.Ruffels@kent.ac.uk, T: 01227 827955
Tizard Centre, University of Kent, Woodlands,
Canterbury, CT2 7LR

Information sheet

Dear Advocate,

You are invited to take part in the doctoral research 'Self-advocacy and the disability movement.' The research is led by Gabor Petri PhD Student at the Tizard Centre, University of Kent.

Gabor Petri is supervised by Dr Julie Beadle-Brown and Dr Jill Bradshaw.

You participation in the study will be completely voluntary. So that you can decide whether or not you want to take part, please read the information below.

The purpose of the study is to explore how self-advocacy is seen by disability advocates today. The study will be carried out both in England and in Hungary.

You were contacted because you are active in disability advocacy. This study will look at how disability advocates think about self-advocacy. I am interested in your views and opinions.

You will be asked to participate at an interview with Gabor.

The interview will be held at xxx and will take about 60 minutes. The meeting will be recorded on Dictaphone and records will be kept until Gabor completes his doctoral degree.

If you would like to take part in the study, please sign fill in the consent form at the end of this letter and send it back to Gabor Petri. You can send it by post or you can scan it and email it back. If you don't want to take part in the study, you do not have to do anything.

You do not have to take part if you do not want to. If you say yes now but you change your mind later, please let Gabor know. If you do not want to be in the research any more, Gabor will delete your answers and will not include them in the study.

All that you say or contribute during the study will be kept confidential. No participants will be identifiable in the doctoral thesis, except when current abuse is disclosed by participants – in these cases Gabor Petri will discuss the details with you and his supervisors.

All the data the researcher will collect will be kept securely.

Gabor Petri is a doctoral student and he will use the data for his doctoral research. He will collect and analyse the data himself. A doctoral thesis will be written up by him, and parts of his thesis may also be published in scientific journals or presented at conferences. At the end of his research he will send you a summary of the findings and you are free to ask for more information from him if you are interested. You will remain anonymous in the thesis.

The project runs as a doctoral study and it is backed by the Tizard Centre. The study was approved by the Tizard Ethics Committee. If you have any queries about the ethics, you can contact the Tizard Centre. The final report (doctoral thesis) will be held at the University of Kent as well.

If you feel concerned at any point of the study you can talk to Gabor Petri directly who will try to answer your questions. If you want to talk to someone else, you can contact Dr Julie Beadle-Brown, who will handle the information you give her confidentially and will try to help solving your problem.

Should you have any questions or you are just interested to know more about the study you can ring Gabor Petri on 01227 824770 or send an email to gp249@kent.ac.uk.

Gabor Petri
PhD Student
Tizard Centre, University of Kent,
Woodlands, Giles Lane Canterbury, Kent CT2 7LR.
This research has been approved by the Tizard Centre Ethics Committee.

Researcher: Gabor Petri
Email: gp249@kent.ac.uk, T: 01227 824770
Supervisor: Julie-Beadle Brown
Email: J.D.Beadle-Brown@kent.ac.uk, T: 01227 827763
Tizard Ethics Committee
Email: J.Ruffels@kent.ac.uk, T: 01227 827955
Tizard Centre, University of Kent, Cornwallis East, Kent CT2 7LR

Information sheet

Dear Advocate,

You are invited to take part in the doctoral research 'Self-advocacy and the disability movement.' The research is led by Gabor Petri PhD Student at the Tizard Centre, University of Kent.

Gabor Petri is supervised by Dr Julie Beadle-Brown and Dr Jill Bradshaw.

You participation in the study will be completely voluntary. So that you can decide whether or not you want to take part, please read the information below.

The purpose of the study is to explore how self-advocacy is seen by disability advocates today. The study will be carried out both in England and in Hungary.

You were contacted because you are active in disability advocacy. This study will look at how disability advocates think about self-advocacy. I am interested in your views and opinions.

You will be asked to participate at a focus group discussion where other disability advocates will also be present.

The meeting will be held at xxx and will take about 60 minutes. The meeting will be recorded on Dictaphone and records will be kept until Gabor completes his doctoral degree.

If you would like to take part in the study, please sign fill in the consent form at the end of this letter and send it back to Gabor Petri. You can send it by post or you can scan it and email it back. If you don't want to take part in the study, you do not have to do anything.

You do not have to take part if you do not want to. If you say yes now but you change your mind later, please let Gabor know. If you do not want to be in the research any more, Gabor will delete your answers and will not include them in the study.

All that you say or contribute during the study will be kept confidential. No participants will be identifiable in the doctoral thesis. In cases when current abuse is disclosed by participants Gabor will discuss the details with you and his supervisors. All the data the researcher will collect will be kept securely.

Gabor Petri is a doctoral student and he will use the data for his doctoral research. He will collect and analyse the data himself. A doctoral thesis will be written up by him, and parts of his thesis may

also be published in scientific journals or presented at conferences. At the end of his research he will send you a summary of the findings and you are free to ask for more information from him if you are interested. You will remain anonymous in the thesis and in any presentations or article he writes.

The project runs as a doctoral study and it is backed by the Tizard Centre. The study was approved by the Tizard Ethics Committee. If you have any queries about the ethics, you can contact the Tizard Centre (Jo Ruffels, J.Ruffels@kent.ac.uk, T: 01227 827955). The final report (doctoral thesis) will be held at the University of Kent Library.

If you feel concerned at any point of the study you can talk to Gabor Petri directly who will try to answer your questions. If you want to talk to someone else, you can contact Dr Julie Beadle-Brown, who will handle the information you give her confidentially and will try to help solve your problem.

Should you have any questions or you are just interested to know more about the study you can ring Gabor Petri on 01227 824770 or send an email to gp249@kent.ac.uk.

Gabor Petri
PhD Student
Tizard Centre, University of Kent,
Cornwallis East, Kent, CT2 7LR

This research has been approved by the Tizard Centre Ethics Committee.

Appendix 9. Information sheet, easy read (English)

Researcher: Gabor Petri
Email: gp249@kent.ac.uk, T: 01227 824770
Supervisor: Julie-Beadle Brown
Email: J.D.Beadle-Brown@kent.ac.uk, T: 01227 827763
Tizard Ethics Committee
Email: J.Ruffels@kent.ac.uk, T: 01227 827955
Tizard Centre, University of Kent, Woodlands,
Canterbury, CT2 7LR

TIZARD
University of Kent

Information sheet

My name is Gabor Petri

I am doing research about self-advocacy

I will look at how self-advocates speak up

And what support they need to be able to speak up
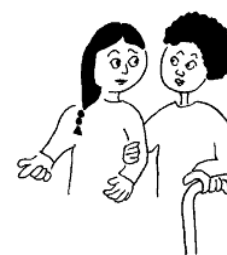
I will ask people to tell me what they think

I will ask questions about

   Why you decided to become self-advocate

   What is difficult for you

   What is helpful when you speak up

I will listen and write down what you tell me

I may record meetings on a machine.

But I will ask you first if this is OK.

244

You can come and talk to me about what you thin

I will invite people to a group to talk about self-advo

Everything you will tell will be kept private,

unless you say something about current abuse.

If you say something about current harm,

I will discuss it with my supervisors.

I will write a report about the information you tell me.

I will not use any names when I write about the research

The report may also be published in a journal or book

If you want to come and talk to me, let me know!

There is a form attached you can fill in.

Or ask someone to help you fill it in.

You can write to me or phone me
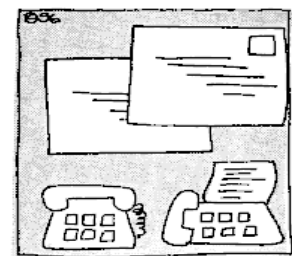
If you have questions you can ring me on 01227 824770 or ask someone to help you write to me:

Gabor Petri
PhD Student, Email: gp249@kent.ac.uk
Tizard Centre, University of Kent, Woodlands, Giles Lane Canterbury, Kent CT2 7LR.
This research has been approved by the Tizard Centre Ethics Committee.

Appendix 10. First contact sheet (English)

Researcher: Gabor Petri
Email: gp249@kent.ac.uk, T: 01227 824770
Supervisor: Julie-Beadle Brown
Email: J.D.Beadle-Brown@kent.ac.uk, T: 01227 827763
Tizard Ethics Committee
Email: J.ruffels@kent.ac.uk , T: 01227827955
Tizard Centre, University of Kent
Woodlands, Giles Lane, Canterbury, CT2 7LR

TIZARD
University of **Kent**

First contact sheet

My name is Gabor Petri and I am a PhD student at the University of Kent.

I am working on my doctoral research project that will look at how self-advocates with intellectual disabilities and autism are seen within the disability movement today. I will try to find how they can be helped to advocate for themselves.

I will go to organisations of disabled people and ask them how they work together with self-advocates. I will also ask different people, for example parents, professional advocates and self-advocates who have intellectual disability or autism.

I will ask people to tell me what they think about self-advocacy.

If you participate in my study and answer my questions then you will help me to collect data so I can successfully finish my PhD.

When I finish my PhD I will publish the findings so people can see what are the biggest problems self-advocates face today, and how they can be helped to stand up for themselves.

If you have any questions please contact me. You can also contact my supervisor, Dr. Julie Beadle-Brown and you can speak with her about my work.

My mobile phone number is 07762 326821 and my email is gp249@kent.ac.uk.

I am happy to answer any questions.

Yours sincerely

Gabor Petri

This research has been approved by the Tizard Centre Ethics Committee.

Appendix 11. Consent form (English)

Researcher: Gabor Petri
Email: gp249@kent.ac.uk, T: 01227 824770
Supervisor: Julie-Beadle Brown
Email: J.D.Beadle-Brown@kent.ac.uk, T: 01227 827763
Tizard Ethics Committee
Email: J.Ruffels@kent.ac.uk, T: 01227 827955
Tizard Centre, University of Kent, Cornwallis East

TIZARD University of Kent

'Self-advocacy and the disability movement' research project

Consent form	
	Please tick here
I understood the information provided on the Information sheet.	☐
I understand that I can withdraw from the project any time.	☐
I understand that my participation is voluntary.	☐
I agree to take part in the study and participate in the focus group / interview.	☐
I agree to have my contribution recorded.	☐
I agree that what I say may be included in publications.	☐
I would like to remain anonymous.	☐

--------------	-------------------	-------------------
Date	Name	Signature

This consent form has been approved by the Tizard Ethics Committee.

If you are interested to know more about my study you can ring me on 01227 824770 or ask someone to help you write to me:

Email: gp249@kent.ac.uk
Tizard Centre, University of Kent,
Cornwallis East, Canterbury, Kent CT2 7LR.
Gabor Petri, PhD Student

248

Researcher: Gabor Petri
Email: gp249@kent.ac.uk, T: 01227 824770
Supervisor: Julie-Beadle Brown
Email: J.D.Beadle-Brown@kent.ac.uk, T: 01227 827763
Tizard Ethics Committee
Email: J.Ruffels@kent.ac.uk, T: 01227 827955
Tizard Centre, University of Kent, Woodlands, Canterbury, CT2 7LR

CONSENT FORM

The research has been explained to me.

	YES!	No Way
It is okay that Gabor will come and speak with me and others.		
It is okay that Gabor takes notes and records what we say.		

I know that I can say "no"

or refuse to answer any of the questions.

At the meeting, there may be others

who will talk about their experiences.

The meeting will be recorded.

	YES!	No Way
It is okay that there will be other people at the meeting who talk about their experiences.		
I would like my support worker to join the meeting.		
It is okay that there will be other support workers at the meeting who help others.		

-------------------------------   ---------------

Signed   Date

This consent form has been approved by the Tizard Centre Ethics Committee.

If you are interested to know more about my study you can ring me on 01227 824770 or ask someone to help you write to me:

Email: gp249@kent.ac.uk
Tizard Centre, University of Kent,
Woodlands, Giles Lane Canterbury, Kent CT2 7LR.
Gabor Petri, PhD Student

Appendix 13. Consent form, interview, easy read version (English)

TIZARD
University of **Kent**

Researcher: Gabor Petri
Email: gp249@kent.ac.uk, T: 01227 824770
Supervisor: Julie-Beadle Brown
Email: J.D.Beadle-Brown@kent.ac.uk, T:
01227 827763
Tizard Ethics Committee
Email: J.Ruffels@kent.ac.uk, T: 01227 827955
Tizard Centre, University of Kent, Woodlands,
Canterbury, CT2 7LR

CONSENT FORM FOR INTERVIEW PARTICIPANTS

The research has been explained to me.

	YES!	No Way
It is okay that Gabor will come and speak with me.		
It is okay that Gabor takes notes and records what we say.		
I would like to remain anonymous.		

I know that I can say 'no' or refuse to answer any of the questions.

-------------------------------   ----------------------------
Signed   Date

This consent form has been approved by the Tizard Centre Ethics Committee.

If you are interested to know more about my study you can ring me on 01227 824770 or ask someone to help you write to me: Email: gp249@kent.ac.uk
Tizard Centre, University of Kent, Woodlands, Giles Lane Canterbury, Kent CT2 7LR.
Gabor Petri, PhD Student

Appendix 14. Complaint form (English)

Researcher: Gabor Petri
Email: gp249@kent.ac.uk, T: 01227 824770
Supervisor: Julie-Beadle Brown
Email: J.D.Beadle-Brown@kent.ac.uk, T: 01227 827763
Tizard Ethics Committee
Email: J.Ruffels@kent.ac.uk, T: 01227 827955
Tizard Centre, University of Kent

<u>COMPLAINT FORM</u>

Thank you for participating in the study "Self-advocacy and the disability movement".

I hope everything was alright during the meetings. However, if you feel you have any concerns about anything, please do feel free to contact me. My email is: gp249@kent.ac.uk. You can also call me, my phone number is 01227824770.

In case you wish to contact someone else about your concerns, you can talk to my supervisor, Julie Beadle-Brown. Her phone number is 01227 827763 and her email is J.D.Beadle-Brown@kent.ac.uk.

If you prefer contacting the Tizard Ethics Committee, you can write to them to J.ruffels@kent.ac.uk or call them on phone: 01227827955.

If you feel you need help to make a complaint, ask for someone's help. By telling us about your concerns we will be able to improve our research.

Some complaints are big. Some complaints are small. It is always OK to tell us about it.

Thank you for participating in the study!

Gabor Petri

PhD Student

Tizard Centre, University of Kent, Canterbury, CT2 7LR

This research has been approved by the Tizard Ethics Committee.

Appendix 15. Complaint form, easy read (English)

Researcher: Gabor Petri
Email: gp249@kent.ac.uk, T: 01227 824770
Supervisor: Julie-Beadle Brown
Email: J.D.Beadle-Brown@kent.ac.uk, T: 01227 827763
Tizard Ethics Committee
Email: J.Ruffels@kent.ac.uk, T: 01227827955
Tizard Centre, University of Kent, Woodlands,
Canterbury, CT2 7LR

COMPLAINTS FORM

This is Gabor Petri

Thank you for agreeing to talk to Gabor.

We hope everything was alright when you talked to Gabor.

It is Gabor's job to treat people properly.

He should be polite and respectful

He should treat you as an adult

© Can Stock Photo

253

He should make sure you know what is happening

If you did not like the way Gabor treated you, you can complain.

HOW TO COMPLAIN

The first thing you could do is tell Gabor himself about it.

Or maybe you would prefer to talk to someone else.

You can phone Gabor's boss.

Her name is Julie Beadle-Brown.

Her phone number is 01227 827763.

j.d.beadle-brown@kent.ac.uk

Julie Beadle-Brown will listen to you carefully.

Then she will need to talk to other people.

She will get in touch with you to.

If something bad happened when Gabor was talking to you, let us know.

We want to learn how to stop this happening again.

You will not get into trouble if you tell us.

Some complaints are big.

Some complaints are small.

It's always OK to tell us about it.

Thank you.

Tizard Centre Research Ethics Committee

This research has been approved by the Tizard Ethics Committee.

255

Kutató: Gabor Petri
Email: gp249@kent.ac.uk, T: 20 4949104
Témavezető: Julie-Beadle Brown
Email: J.D.Beadle-Brown@kent.ac.uk, T: 01227
827763
Tizard Etikai Bizottság
Email: J.Ruffels@kent.ac.uk, T: 01227 827955
Tizard Centre, University of Kent, Woodlands,
Canterbury, CT2 7LR

Információ a kutatásról

Kedves Résztvevő!

Ezennel felkérem, hogy vegyen részt az *Önérvényesítés és a fogyatékos emberek mozgalma* c. doktori kutatásban. A kutatást én, Petri Gábor, a University of Kent PhD-hallgatója vezetem, Dr. Julie Beadle-Brown és Dr. Jill Bradshaw témavezetése alatt.

Az Ön részvétele a kutatásban teljesen önkéntes. Kérem, olvassa el a következőket.

A kutatás célja, hogy feltérképezze, miként látják a fogyatékos emberek civil mozgalmainak résztvevői az önérvényesítést. A kutatás Angliára és Magyarországra fókuszál, és az Ön véleményére is számítok, ezért ezúton interjúra kérem fel.

Az interjú kb. egy órát vesz majd igénybe, és diktafonnal rögzítem. A felvételeket a doktori kutatás befejezéséig fogom tárolni.

Amennyiben vállalja az interjút, **kérem, a mellékelt beleegyező nyilatkozatot aláírva juttassa el hozzám – válaszát emailen vagy postán is elküldheti, a nyilatkozatot ez esetben az interjú alkalmával írjuk alá**. Ha nem vállalja az interjút, nem kell tennie semmit.

Részvétele önkéntes, és bármikor meggondolhatja magát; ha ez megtörténne, értesítsen engem az interjú előtt. Akár az interjú után is közölheti, hogy szeretne visszalépni, ez esetben én a felvett interjút törölni fogom.

Az interjú teljes egészében bizalmas adatnak minősül, és egyetlen interjúalanyt sem lehet majd azonosítani a kutatási jelentésben. Ez alól kivételt képez, ha jelenleg is folyó abúzusról beszél nekem – az ilyen eseteket a témavezetőimmel külön is meg kell beszélnem.

A kutatás során felvett adatokat teljes egészében titkosan kezelem, és biztonságosan tárolom majd. A felvett interjúkat magam elemzem majd és azokból doktori dolgozat készül, amelynek részeit hazai vagy külföldi folyóiratok is publikálhatják. A kutatás eredményeit konferenciákon is igyekszem majd bemutatni. A kutatás végén egy összefoglalót is készítek, amelyet Önnek is elküldök majd – ha érdekli, további részleteket is szívesen megosztok majd Önnel a kutatás eredményeiről. Az Ön anonimitása a doktori dolgozatban és az azokból készült anyagokban teljes egészében biztosítva lesz.

Jelen doktori kutatást a University of Kent (Anglia) Tizard Centre-je támogatja. A kutatást jóváhagyta a Tizard Centre Etikai bizottsága. Ha bármilyen, etikai kérdésekkel kapcsolatos problémája vagy kérdése van, forduljon a Tizard Centre-hez.

Ha az interjú vagy a velem való kommunikáció bármely pontján úgy érzi, nem megfelelően viszonyulok Önhöz vagy az ön által elmondottakhoz, kérem, bátran ossza meg velem gondolatait. Ha mégis mással szeretne beszélni, akkor témavezetőm, Julie Beadle-Brown áll rendelkezésére, akiben megbízhat, mert az elmondottakat bizalmasan kezeli majd. Elérhetőségét a fejlécben találja.

Ha már most kérdése van az interjúval vagy a kutatás bármely részletével kapcsolatban, forduljon hozzám a 06 20 4949104-es számon vagy a gp249@kent.ac.uk emailen.

Petri Gábor
PhD hallgató
Tizard Centre, University of Kent,
Woodlands, Giles Lane Canterbury, Kent CT2 7LR.
A kutatást jóváhagyta a University of Kent Tizard Centre Etikai bizottsága.

Kutató: Petri Gábor
Email: gp249@kent.ac.uk, T: 20 4949104
Témavezető: Julie-Beadle Brown
Email: J.D.Beadle-Brown@kent.ac.uk, T: 01227
827763
Tizard Etikai Bizottság
Email: J.Ruffels@kent.ac.uk, T: 01227 827955
Tizard Centre, University of Kent, Woodlands,
Canterbury, CT2 7LR

Információ a kutatásról

Kedves Résztvevő!

Ezennel felkérem, hogy vegyen részt az *Önérvényesítés és a fogyatékos emberek mozgalma* c. doktori kutatásban. A kutatást én, Petri Gábor, a University of Kent PhD-hallgatója vezetem, Dr. Julie Beadle-Brown és Dr. Jill Bradshaw témavezetése alatt.

Az Ön részvétele a kutatásban teljesen önkéntes. Kérem, olvassa el a következőket.

A kutatás célja, hogy feltérképezze, miként látják a fogyatékos emberek civil mozgalmainak résztvevői az értelmi fogyatékos vagy autista emberek érdekvédelmét, önérvényesítését. A kutatás Angliára és Magyarországra fókuszál, és az Ön véleményére is számítok, ezért ezúton fókuszcsoportban való részvételre kérem fel.

Az interjú kb. egy órát vesz majd igénybe, és diktafonnal rögzítem. A felvételeket a doktori kutatás befejezéséig fogom tárolni.

Amennyiben vállalja az interjút, **kérem, a mellékelt beleegyező nyilatkozatot aláírva juttassa el hozzám – válaszát emailen vagy postán is elküldheti, de a nyilatkozatot az interjú alkalmával is átadhatja** (helyben is lesznek nyomtatott példányok). Ha nem vállalja az interjút, nem kell tennie semmit.

Részvétele önkéntes, és bármikor meggondolhatja magát; ha ez megtörténne, értesítsen engem a fókuszcsoport előtt. Akár a fókuszcsoport után is közölheti, hogy szeretne visszalépni, ez esetben az Ön által mondottakat figyelmen kívül hagyom, illetve lehetőség szerint törlöm.

Az interjú teljes egészében bizalmas adatnak minősül, és egyetlen interjúalanyt sem lehet majd azonosítani a kutatási jelentésben. Ez alól kivételt képez, ha jelenleg is folyó abúzusról beszél nekem – az ilyen eseteket a témavezetőimmel külön is meg kell beszélnem.

A kutatás során felvett adatokat teljes egészében titkosan kezelem, és biztonságosan tárolom majd. A felvett interjúkat magam elemzem majd és azokból doktori dolgozat készül, amelynek részeit hazai vagy külföldi folyóiratok is publikálják. A kutatás eredményeit konferenciákon is igyekszem majd bemutatni. A kutatás végén egy összefoglalót is készítek, amelyet Önnek is elküldök majd, ha részt vesz. Ha érdekli, további részleteket is szívesen megosztok majd Önnel a kutatás eredményeiről. Az Ön anonimitása a doktori dolgozatban és az azokból készült anyagokban teljes egészében biztosítva lesz.

Jelen doktori kutatást a University of Kent Tizard Centre-je (Anglia) támogatja. A kutatást jóváhagyta a Tizard Centre Etikai bizottsága. Ha bármilyen, etikai kérdésekkel kapcsolatos problémája vagy kérdése van, forduljon a Tizard Centre-hez.

Ha az interjú vagy a velem való kommunikáció bármely pontján úgy érzi, nem megfelelően viszonyulok Önhöz vagy az ön által elmondottakhoz, kérem, bátran ossza meg velem gondolatait. Ha mégis mással szeretne beszélni, akkor témavezetőm, Julie Beadle-Brown áll rendelkezésére, akiben megbízhat, mert az elmondottakat bizalmasan kezeli majd. Elérhetőségét a fejlécben találja.

Ha már most kérdése van az interjúval vagy a kutatás bármely részletével kapcsolatban, forduljon hozzám a 06 20 4949104-es számon vagy a gp249@kent.ac.uk emailen.

Petri Gábor
PhD hallgató
Tizard Centre, University of Kent,
Woodlands, Giles Lane Canterbury, Kent CT2 7LR.
A kutatást jóváhagyta a University of Kent Tizard Centre Etikai bizottsága.

Kutató: Gabor Petri
Email: gp249@kent.ac.uk, T: 01227 824770
Témavezető: Julie-Beadle Brown
Email: J.D.Beadle-Brown@kent.ac.uk, T: 01227 827763
Tizard Etikai Bizottság
Email: J.Ruffels@kent.ac.uk, T: 01227 827955
Tizard Centre, University of Kent, Woodlands,
Canterbury, CT2 7LR

Információs lap

Petri Gábornak hívnak

Az önérvényesítésről csinálok kutatást

Arra vagyok kiváncsi, hogy az emberek hogyan állnak ki magukért.

És hogy mire van szükségük ahhoz, hogy kiálljanak magukért.

Embereket kérek meg arra, mondják el erről a vélemény

Ilyen kérdéseket teszek majd fel

Mi a jó az önérvényesítő munkában?

Mi okoz nehézséget?

Miben van szükség segítségre?

Meghallgatom, amit mondasz és jegyzeteket készítek

Fel is veszem a beszélgetést.

Persze csak ha beleegyezel.

Ha bármilyen kérdésed van, szívesen válaszolok.

Más önérvényesítők is jelen lesznek a beszélgetésen.

Minden, ami elhangzik, közöttünk marad,

kivéve, ha arról mesélsz, hogy valakit bántalmaznak.

Ha arról mesélsz, hogy valakit bántalmaznak,

Azt meg kell beszélnem a tanáraimmal.

Egy egyetemi dolgozatot írok abból, amit beszélgetünk.

Amit leírok, abban senkinek a neve nem lesz benne.

A dolgozat részeit talán könyvekben is kiadják majd.

Nagyon örülnék, ha eljönnél a beszélgetésre!

Küldök egy másik lapot is, amin jelezheted, hogy eljössz.

Ha kell, kérj segítséget a kitöltéshez.

Írhatsz is nekem, de telefonálhatsz is.
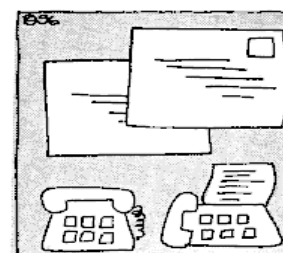
Ha bármi kérdésed van, hívj bátran a 06 20 4949104 számon. Vagy kérj meg valakit, hogy segítsen felhívni.

Petri Gábor
Doktori hallgató, Email: gp249@kent.ac.uk
Tizard Centre, University of Kent, Woodlands, Giles Lane Canterbury, Kent CT2 7LR.
A kutatást jóváhagyta a Tizard Centre Etikai Bizottsága.

Appendix 19. Elfogadó nyilatkozat, interjú [Consent form, interview participants] (Hungarian)

Kutató: Petri Gábor
Email: gp249@kent.ac.uk, T: 06 20 4949104
Témavezető: Julie-Beadle Brown
Email: J.D.Beadle-Brown@kent.ac.uk,
T: + 44 1227 827763
Tizard Etikai Bizottság
Email: J.Ruffels@kent.ac.uk,
T: +44 1227 827955
Tizard Centre, University of Kent, Woodlands, Canterbury, CT2 7LR

<u>Önérvényesítés és a fogyatékos emberek mozgalma</u>

Beleegyező nyilatkozat

	X-szel jelölje
Elolvastam az Információs lapon szereplő tájékoztatást.	☐
Megértettem, hogy bármikor visszaléphetek a kutatásból.	☐
Megértettem, hogy részvételem a kutatásban önkéntes.	☐
Szívesen részt veszek az interjún és beleegyezem, hogy az interjú diktafonon rögzítve legyen.	☐
Elfogadom, hogy az általam elmondottak alapján publikáció készül.	☐
Szeretnék névtelen maradni a kutatási jelentésben.	☐

--------------   --------------------   ---------------------
Dátum   Név (nyomtatott)   Aláírás

Ezt a nyilatkozatot jóváhagyta a Tizard Etikai Bizottság.

Ha kérdése van, kérem, jelezze az alábbi elérhetőségek valamelyikén.

Email: gp249@kent.ac.uk
Telefon: 06 20 4949104
Tizard Centre, University of Kent,
Woodlands, Giles Lane Canterbury, Kent CT2 7LR.
Gabor Petri, PhD hallgató

Appendix 20. Elfogadó nyilatkozat, könnyen érthető [Consent form, focus group, easy read version] (Hungarian)

Kutató: Gabor Petri
Email: gp249@kent.ac.uk, T: 01227 824770
Témavezető: Julie-Beadle Brown
Email: J.D.Beadle-Brown@kent.ac.uk, T: 01227 827763
Tizard Etikai Bizottság
Email: J.Ruffels@kent.ac.uk, T: 01227 827955
Tizard Centre, University of Kent, Woodlands, Canterbury, CT2 7LR

Elfogadó nyilatkozat

Elmagyarázták nekem a kutatás lényegét.

	YES!	No Way
Rendben van, hogy Gábor beszélget velem és másokkal.		
Rendben van, hogy Gábor felveszi a beszélgetést és leír dolgokat.		

Tudom, hogy nem kötelező minden kérdésre válaszolni.

A beszélgetésen mások is jelen lesznek.

Például akiknek hasonló gondjaik vannak.

	YES!	No Way
Rendben van, hogy a beszélgetésen mások is jelen lesznek.		
Szeretném, ha a segítőm is ott lenne a beszélgetésen.		
Rendben van, ha mások segítői eljönnek.		

------------------------------   ---------------------------

Aláírás   Dátum

Ezt a nyilatkozatot jóváhagyta a Tizard Centre Etikai Bizottsága.

Bármilyen kérdéssel fel lehet hívni Petri Gábort a 06 20 4949104-es telefonon.
Vagy emailt lehet neki küldeni az alábbi címre.

Email: gp249@kent.ac.uk
Tizard Centre, University of Kent,
Woodlands, Giles Lane Canterbury, Kent CT2 7LR.
Gabor Petri, PhD hallgató

Kutató: Petri Gábor
Email: gp249@kent.ac.uk, T: 06 20 4949104
Témavezető: Julie-Beadle Brown
Email: J.D.Beadle-Brown@kent.ac.uk,
T: + 44 1227 827763
Tizard Etikai Bizottság
Email: J.Ruffels@kent.ac.uk,
T: +44 1227 827955
Tizard Centre, University of Kent, Woodlands,
Canterbury, CT2 7LR

Önérvényesítés és a fogyatékos emberek mozgalma

Beleegyező nyilatkozat	
	X-szel jelölje
Elolvastam az Információs lapon szereplő tájékoztatást.	☐
Megértettem, hogy bármikor visszaléphetek a kutatásból.	☐
Megértettem, hogy részvételem a kutatásban önkéntes.	☐
Örömmel részt veszek az fókuszcsoporton és beleegyezem, hogy az diktafonon rögzítve legyen.	☐
Elfogadom, hogy az általam elmondottak alapján publikáció készül.	☐
Szeretnék névtelen maradni a kutatási jelentésben.	☐

--------------   --------------------   --------------------
Dátum   Név (nyomtatott)   Aláírás

Ezt a nyilatkozatot jóváhagyta a Tizard Centre Etikai Bizottsága.

Ha kérdése van, kérem, jelezze az alábbi elérhetőségek valamelyikén.

Email: gp249@kent.ac.uk
Telefon: 06 20 4949104
Tizard Centre, University of Kent,
Woodlands, Giles Lane Canterbury, Kent CT2 7LR.
Gabor Petri, PhD hallgató

Researcher: Gabor Petri
Email: gp249@kent.ac.uk, T: 01227 824770
Supervisor: Julie-Beadle Brown
Email: J.D.Beadle-Brown@kent.ac.uk, T: 01227 827763
Tizard Ethics Committee
Email: J.Ruffels@kent.ac.uk, T: 01227 827955
Tizard Centre, University of Kent, Woodlands,
Canterbury, CT2 7LR

Panasztételi lap

Köszönöm, hogy részt vesz a doktori kutatásomban.

Remélem, mindent megfelelőnek talált a kommunikációnk és az interjú/fókuszcsoport során. Ha mégis úgy érzi, hogy valami nem megfelelően történt, kérem, nyugodtan jelezze nekem emailen (gp249@kent.ac.uk) vagy telefonon (T: 06 20 4949104).

Ha nem velem, hanem mással szeretne beszélni, témavezetőm Julie Beadle-Brown örömmel válaszol kérdéseire, problémájára. Telefonszáma 00 44 1227 827763, emailje pedig J.D.Beadle-Brown@kent.ac.uk.

Ha közvetlenül a Tizard Etikai Bizottsághoz szeretne fordulni, azt a következő elérhetőségeken teheti meg: J.ruffels@kent.ac.uk emailen vagy telefonon 00 44 1227 827955.

Ha problémájának megfogalmazásához szüksége lenne segitségre, kérem, bátran jelezze. Minden megfogalmazott kérést vagy jelzést komolyan veszünk, és bizalmasan kezelünk. Bármi is legyen az, amiben hozzánk fordul, tegye meg bátran.

Még egyszer köszönöm, hogy részt vett a kutatásban.

Petri Gábor

PhD hallgató

Tizard Centre, University of Kent, Woodlands,

Canterbury, CT2 7LR

A kutatást jóváhagyta a Tizard Centre Etikai Bizottsága.

Kutató: Gabor Petri
Email: gp249@kent.ac.uk,
Témavezető: Julie-Beadle Brown
Email: J.D.Beadle-Brown@kent.ac.uk, T: 01227 827763
Tizard Ethics Committee
Email: J.Ruffels@kent.ac.uk, T: 01227827955
Tizard Centre, University of Kent, Woodlands,
Canterbury, CT2 7LR

PANASZTÉTELI LAP

Ez itt Gabor Petri

Köszönjük, hogy beszéltél Gáborral.

Reméljük, minden rendben volt.

Gábornak kötelessége udvariasan bánni mindenkivel.

Fontos, hogy felnőttként kezeljen mindenkit.

Fontos, hogy megadja a tiszteletet.

Fontos, hogy minden kérdésedre is válaszoljon.

Ha Gábor mégsem volt udvarias, vagy más panaszod van,

mondd el.

HOGYAN TEHETSZ PANASZT?

Először is beszéld meg Gáborral, mi volt a gond.

Ha mással szeretnél beszélni, azt is megteheted.
Fel tudod hívni Gábor főnökét.
Az ő neve Julie Beadle-Brown.
Vele angolul kell beszélni, ezért kérj segítséget, ha őt hívod.

Telefonszáma +44 1227 827763.

Ha gondolod, írhatsz is neki emailt (angolul):
j.d.beadle-brown@kent.ac.uk
Julie Beadle-Brown minden emailt szívesen olvas.

Ha panaszt teszel, ő át fogja gondolni.

Másokkal is beszél majd erről.

Válaszolni fog az emailedre.

Ha szerinted Gábor valami rosszat tett, mindenképpen írj Julie-nak.

Fontos, hogy legközelebb ne történjen ilyen.

Ha írsz Julie-nak, nyugodj meg, semmi baj nem ér téged.

Vannak nagyobb problémák.

Vannak kisebb problémák is.

De fontos, hogy elmondd, ha problémád volt.

Köszönjük.

Tizard Centre Etikai Bizottság

Ezt a kutatást jóváhagyta a Tizard Centre Etikai Bizottsága.

Appendix 24. Full list of practices (without participant categories and themes)

Practices of advocacy and self-advocacy		
Learning how to introduce ourselves in hospitals, offices, schools, at a party etc.	Passing on information	Writing letters to authorities
	Giving voice to peers	Reading the law
Getting a to know ourselves and more about others and our environment	Getting help to protect ourselves	Protecting rights
	Putting things on or editing a website	Speaking for other families
Learning how to handle money		Organising meetings
Doing 'nothing about us without us'	Writing things up	Bringing together parents
	Giving trainings	Making sure my kid is OK in the class
Standing up for our rights every day	Learning things	
	Speaking with others	Representing the interest of their children
Gaining confidence and be visible in the world	Developing new skills	
	Becoming independent	Representing the interest of the whole family
Exchanging information / experience with peers	Being able to protect yourself	
	Reading things on the internet	Writing a blog
Helping each other	Writing up articles	Writing books, articles
Going to conferences and meeting others	Learning how to handle conflicts	Being on social media, Twitter, Facebook
	Fighting for benefits	
Preparing for conferences	Telling people what autism is (what it is not)	Getting in touch with other parents on social media
Telling politicians what we want		
Protecting your peers	Passing on information to non-autistic people	Establishing an organisation
Writing letters		Speaking in the media
Administration in organisations	Issuing statements (as in policy context)	Going to conferences
Myth-busting about autism		Speaking at conferences
Reading on autism and other stuff	Giving interviews in media (press, tv)	Trying to change the law, lobbying
Helping autistic peers		Developing skills (law, financial, leadership, negotiation skills etc)
Developing websites	Doing research on therapies or evidence-based interventions	
Making films, videos		Supporting self-advocates
Developing new skills, learning	Defending rights, using the law	Teaching advocacy skills
Doing graphic design	Making videos, putting them online	Supporting their children
Raising public awareness, e.g. by giving lectures		Influencing policies or laws
	Working together as a community (with other autistic people)	Giving trainings to professionals
Sharing experiences with peers		Travelling a lot (e.g. to conferences)
Blogging, vlogging	Supporting each other, even just solidarity	
Being active on social media		Not accepting refusal by authorities
Networking, meeting others	Educating neurotypical people about autism	
Learning about human rights & the movement		Going to workshops to gain skills
	Starting or signing petitions	Paperwork or administration of cases
Organising rallies	Teaching about various issues	
Making and using leaflets, fliers etc	Telling people about their rights	Participating in formal government consultations
	Litigating cases	
Pushing for legal changes, lobbying	Doing NHS complaints or helping people putting together care plans	Competing with other advocacy organisations
Participating in drafting laws and policies		Managing an organisation
	Making information accessible to everyone	Entering confrontations or conflicts
Organising conferences and meetings	Structuring information	Running legal aid services
	Going to tribunals	Making Internet accessible for SAs with LD
Going to authorities, social or health services	Visiting families	
	Supporting clients emotionally	Writing to politicians
Going to ministries and city councils	To train and support self-advocates	Talking things through with clients
		Paperwork at organisations
Doing 'street actions', e.g. rallies, flashmobs etc.		

Lack of influence and participation by self-advocates in organisations acting on their behalf

Advocacy organisations and other bodies that speak on behalf of people with learning difficulties or autistic spectrum conditions tend be led and controlled by non-disabled people rather than by self-advocates, **Gabor Petri**'s doctoral research findings suggest

Background

The disabled people's movement has successfully influenced laws and policies across the world over the past three decades. Today, improved accessibility, progress in deinstitutionalisation and community living, anti-discrimination laws and other policies mark the impact of the continuous advocacy by disabled people's organisations (DPOs).

DPOs are seen as representative voices and are usually led and controlled by people with disabilities. However, there are exceptions – those speaking on behalf of people with autistic spectrum conditions (ASC) and with learning difficulties are usually controlled by parents or professionals.

To date, very few studies have explored what hinders self-advocates' better involvement in their "own" organisations.

This research aims to find factors that help and hinder self-advocates in the disability movement, including in their own organisations.

It will be completed in December 2018. The early findings are presented here.

Key findings

To assess the participation of self-advocates within DPOs and in the disability movement, Arnstein's ladder of

Key messages

- Disabled people's organisations are led and controlled by disabled advocates. However, most of those speaking for people with learning difficulties or autism are still led by non-disabled people.
- Self-advocates, parents and professional advocates feel that self-advocates are often not involved in making decisions about how organisations are run.
- Participation by self-advocates in organisations speaking for them is often tokenistic.
- Self-advocacy and support give people the chance to gain control over their lives.

participation was used (Arnstein, 1969).

Subjects – paid, professional advocates, parents and self-advocates – were asked to place self-advocates on the ladder to show how they saw their participation in the democratic decision-making processes of DPOs, charities or the broader disability movement. A simplified ladder was used for people with learning difficulties. Altogether, 44 people (n=24 in Hungary; n=20 in the UK) took part.

Results were consistent between the UK and Hungary: self-advocates in both countries felt their involvement in the broader advocacy movement of disabled people and in formal organisations was often tokenistic, and they had few opportunities to influence DPOs' decisions.

The views of professional paid advocates and parents were similar; they also

thought DPOs were not ensuring the full participation of people with learning difficulties or ASC in them. Even when people are consulted about issues, their responses are not necessarily considered.

Several self-advocates said they thought most people with learning difficulties or ASCs had "no power" and lacked any opportunity to influence how organisations speaking on their behalf worked. Parents and professional advocates agreed.

One autistic self-advocate in Hungary said basic human rights principles were not respected at all within most DPOs:

"There is the saying 'nothing about us without us', which I think is in the Convention [on the Rights of Persons with Disabilities] itself, and this means they [DPOs] have to involve us, so that we are there in the decisions taken about us. But this is not happening at all."

A British professional advocate, like other participants, emphasised the importance of support for people who wished to speak up:

"We tend to be listening but we actually don't give enough options for them and the support to be truly the way it should."

A Hungarian advocate (who is both a family member of a person with learning difficulties and a professional advocate) highlighted that people with learning difficulties, despite shortcomings, were still more included in DPOs than in broader society:

Appendix 26. Publication of findings 2: Summary of findings on Network Autism by the National Autistic Society, 16 November 2018

National Autistic Society | Network Autism

Search Network Autism:

News   Good practice   Knowledge   About this community   Discussions   Groups   Member directory

News » Self-advocacy within disability organisations

Self-advocacy within disability organisations

A doctoral research project at the Tizard Centre (University of Kent) is looking at how autistic people and people with a learning disability participate in the work of disabled people's organisations, and aims to explore the factors that facilitate or hinder self-advocacy in organisations. The project included 44 participants: self-advocates (both autistic people and people with a learning disability), parent advocates and professional advocates in the UK and in Hungary.

Findings were consistent between the two countries and across all participant groups. Self-advocates, parents and professionals all agreed that autistic people (and people with a learning disability) are usually included in disability organisations in tokenistic ways. They are often only informed about decisions made by organisations, and consultations can be superficial. Some people mentioned good practices, for example where autistic people control organisations. The research article is open-access and appears in the Laws journal.

More from Network Autism

▶ Autistic participation: an interview with Jack Welch and Dr Joe Long
▶ Autism research: an interview with Dr Anna Remington
▶ A Future Made Together: Shaping Autism Research in the UK

274

Autista és értelmi fogyatékos emberek
önérvényesítése, érdekképviselete

Petri Gábor 2006 és 2010 között az AOSZ ügyvezető igazgatója volt. E feladata mellett pályázatok írását és a nemzetközi kapcsolatok tartását is végezte. A szövetség nevének megváltoztatása, új arculatának kialakítása az ő nevéhez fűződik.

Aztán kiment Brüsszelbe ösztöndíjjal, és maradt. Ott sem lett hűtlen a fogyatékos emberek ügyéhez. 2010 és 2014 között az Európai Fogyatékossági Fórum és a brüsszeli Mental Health Europe munkájában vett részt. 2013 óta az Európai Fogyatékosügyi Fórum (EDF) kuratóriumának tagja. Jelenleg a Canterburyben lévő Kenti Egyetemhez tartozó Tizard Center PhD ösztöndíjasa: doktoriját 2019 elején védi meg.

Ennek témájául olyan területet választott, amelyet kevesen kutatnak, noha egyre többet halljuk a fogyatékos és autista emberek szervezeteitől: *Semmit rólunk nélkülünk.* De vannak-e a szervezetek vezetőségében autista vagy fogyatékos emberek? Petri Gábor doktorijának témája az autista és az értelmi fogyatékos emberek önérvényesítése és érdekképviselete.

Kevés ilyen típusú kutatás van, főleg az értelmi fogyatékos emberekkel kapcsolatban. Az autizmus manapság „divatosabb", a velük kapcsolatos kutatásokra hamarabb nyílnak a pénztárcák, sok országban jelentősen nőttek az erre fordított pénzek. 2014-es brit adatok szerint az autizmus területén összesen 94% megy agykutatás, biológiai témák, autizmus okai, kognitív működés és terápiás beavatkozások kutatására. Azaz a klinikai és orvosi kutatások viszik el a pénz nagy részét. Csupán további 5% megy szolgáltatásokkal kapcsolatosokra, és mindössze 1% (!) társadalmi kutatásokra. Arra, hogy az autista emberek és családjaik hogyan élnek, mik a szükségleteik, milyen az iskolai oktatásuk stb. Arra, hogy mint társadalmi lények milyenek, mennyire tudnak részt venni saját életük alakításában, vagy milyen szolgáltatásokat kapnak, már sokkal kevésbé kíváncsiak a kutatók és a kutatások irányáról döntők. Pedig a felmérések

egyértelműen azt mutatják, hogy mind a területen dolgozók, mind a családok és az autista emberek erről látnának szívesen több kutatást. (Azaz: a kutatási forrásokat nem arra adják, amiket az érintettek és családjaik fontosnak tartanak.) Így elmondhatjuk: Petri Gábornak szerencséje volt, mert az egyetem döntnökei fantáziát láttak kutatásának tárgyában.

Kvalitatív kutatását az Egyesült Királyságban és Magyarországon végezte. Adatközlői mindkét országban három csoportba tartoznak: magukra az érintettekre (autista és értelmi fogyatékos emberekre), a családjukra (családtag, szülő), valamint a velük foglalkozó hivatásos érdekvédőkre, beleértve a civil szervezetek mellett a jogvédőket, az információt adókat: pl. családsegítőket stb. Mindezt természetesen összevetve a föllelhető (kevés) szakirodalommal. Elöljáróban érdemes leszögezni, hogy Petri Gábor (és mások szerint is) az érdekérvényesítés a politikai aktivitás megnyilvánulása, és az érdekvédelem milyensége jelentősen befolyásolja a családok által elérhető szolgáltatásokat.

Gábor egyik kiindulópontja: Az elmúlt 30-40 évben kialakultak a fogyatékos emberek nagy reprezentatív szervezetei, amelyek „elhelyezték" magukat különféle pozíciókban, és közelebb kerültek a politikai hatalomhoz is. Ez nem jelentette feltétlenül a központi hatalmat (kormányt). Az évek során politikai szavuk és súlyuk lett. (Például a MEOSZ elérte, hogy az M3-as metró felújításakor minden állomást akadálymentessé tegyenek.) A másik kiindulópontja: nemcsak szavuk lett, hanem már pénzt is kapnak, és a Semmit rólunk nélkülünk elv alapján a fogyatékos emberek is megjelentek a szervezetek vezetésében, pl. vakok, siketek esetében – kivéve a kognitív sérültek érdekeit képviselő szer-

vezeteket: autistákét, értelmi fogyatékosokét. (Az AOSZ elnökségének egyik tagja ASD-vel diagnosztizált – *a szerk.*)

Petri harmadik kiindulópontja: van-e politikai képviselete az értelmi sérült és az autista embereknek? Kivételek ugyan vannak: a nagyon okosak számítanak, de mi van azokkal, akik nem ebbe csoportba tartoznak? Mi lehet az oka annak, hogy az értelmi fogyatékos, az autista személyek kevéssé képviseltetik magukat a civil érdekvédő szervezetekben? Ez nemcsak nálunk van így, Angliában is ez a helyzet. Hol vannak az érdekvédelmi szervezeteken belül az önérvényesítők, és miért nincsenek érdemi vezető szerepekben? Az elkészült interjúk alapján a hipotézise megdőlt, hogy e két csoportban nincsenek aktív önérvényesítők. Vannak, csak épp nem mindig tagozódnak be egyik, őket képviselő civil szervezetbe sem.

44 adatközlője volt összesen (kb. fele Angliából, fele hazánkból): egy-egy órás interjút készített velük, valamint fókuszcsoportos beszélgetéseket, köztük összesen 11 autista és 15 értelmi sérült önérvényesítővel. Az internet megjelenése a fogyatékos és az autista emberek önérvényesítését (is) megkönnyítette. Az autisták többnyire egyedül képviselik magukat, a megkérdezettek töredéke szervezetben. Például egy angol lány videókat készít, és tesz föl a netre arról, hogy milyenek az autisták. Nem az autizmust akarja bemutatni, hanem azt akarja elérni, hogy ne csak autistának tartsák őket, hanem annak, amik még, az autizmusukon túl: anyák, sportolók, gépírók stb. Van, aki blogot ír, előadásokat tart. Egy másik autista fiatal keresztény gyülekezetekben végez felvilágosító munkát, és hamarosan doktori hallgatóként is kutatni fog.

Az értelmi fogyatékos emberek és a szülők a közös, érdekérvényesítő föllépéseket csoportban végzik, mert náluk fontosabbak a hagyományosabb közösségek. (A tévhittel ellentétben autista embereknek is fontos a közösség, de sokan inkább az interneten keresztül vagy kevésbé formálisan tar-

Appendix 28. Publication of findings 4: Interview with Gabor Petri in the popular science radio show 'Professzor Paprika' by Réka Kinga Papp on Klub Radio, aired on 24 September 2018

Az önrendelkezés bekerülési költsége: Petri Gábor brit tudós a ProfPaprikában

Réka Kinga Papp

✓ Subscribed 🔔 981

194 views

➕ Add to ➦ Share ••• More

👍 2 👎 0

Published on 15 Nov 2018
Az autisták és értelmi fogyatékosok maguk is akarnak gondoskodni magukról, és beleszólást akarnak a saját életükbe. Erre a legkevésbé sem

Up next

Illiberalizmus
demokrácia, a
micsoda? Szű
Réka Kinga Papp
78 views

Sergej Rachm
(All-Night Vig
& chorus, Op.
Classical Music