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ORIGINAL ARTICLE

# *'Even a Self-Advocate Needs to Buy Milk'* – Economic Barriers to Self-Advocacy in the Autism and Intellectual Disability Movement

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Autistic people and people with an intellectual disability have been actively involved in disability advocacy; however, it is still often parents and professionals who lead organisations speaking on their behalf. Previous studies have found that autistic self-advocates and self-advocates with an intellectual disability have been systematically marginalised in the disability movement. This article appraises how economic factors influence self-advocates' position within the disability movement, based on qualitative analysis of data collected in two countries, the UK and Hungary. The study found that lack of resources, poverty and unpaid positions at organisations strongly hinder self-advocates' participation in advocacy/disability rights organisations speaking for them. Findings also suggest that practices of disability organisations may contribute to maintaining these barriers.

**Keywords:** disability advocacy; autism; intellectual disability; disability movement; income; poverty; hierarchy

## Introduction

It has been 50 years since the self-advocacy movement of people with intellectual disabilities started in Sweden. In recent decades, many self-advocacy organisations were established by people with intellectual disabilities and autistic people across Europe and beyond. There has been unprecedented surge in newly appointed co-leaders with intellectual disabilities at national charities in countries like Belgium, Hungary, Britain, Italy, and the US (Petri 2018). In 2016, the UN elected Robert Martin, a person with an intellectual disability, as member of a major UN body, the Committee on the Rights of Persons with Disabilities (Inclusion International 2016). Moreover, autistic people have led the neurodiversity movement and have started to challenge mainstream academic claims by 'merging science and advocacy' (Kapp 2020: 10) and by building on the unique knowledge of those who have direct experience in being autistic (Kapp 2020).

Yet, despite these achievements, most disability organisations and charities who speak for people with an intellectual disability and autistic people, are still controlled by parents or professionals. There are strong internal hierarchies within the intellectual disability and autism advocacy movement where autistic people and people with an intellectual disability are often 'locked out' of leadership roles and many other practices crucial to disability advocacy (Petri et al. 2020). Indeed, the slogan 'nothing about us without us' seems to be rather symbolic in most disability organisations because it is still parents and professional advocates who control organisations and speak for people with intellectual disabilities and autistic people while the involvement of self-advocates usually remains tokenistic (Petri et al. 2017). There are only a handful of organisations that are controlled by self-advocates with an intellectual disability or autistic people, and even these organisations often struggle to have their voices heard or just to survive (Pring 2016; Waltz 2013). This article sets out to investigate one core explanatory factor behind this historical marginalisation of self-advocates within the disability movement: the role of funding as a barrier to successful self-advocacy.

Somewhat surprisingly, the role of material resources has been rarely addressed in literature on self-advocacy, even though its salience 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; Montgomery & Baglioni 2020). Funding issues have received some attention in the context of recent decades' neoliberal austerity in Britain (DPAC 2016; Trevisan 2016) but a direct focus on the self-advocacy of autistic people and people with an intellectual disability has been lacking. Academic studies about funding self-advocacy outside Anglo-Saxon countries are particularly absent. The few existing inquiries have appraised funding difficulties of self-advocacy groups in neoliberal Britain (Runswick-Cole & Goodley 2015); stigmatising fund-raising strategies of charities for autistic people (Waltz 2012; McGuire 2012); and the

independence of self-advocacy groups from other organisations or authorities (Buchanan & Walmsley 2006; Bigby 2015). The scarcity of studies on the role of funding self-advocacy is particularly surprising, because leading self-advocates have repeatedly called attention to fund-raising issues of organisations. For example, one autistic self-advocate asked 'Should we continue to support Autism Speaks [a major US charity], which uses corporate and celebrity influence to milk dry the autism community while returning only a tiny fraction of the money it raises for services in the communities from which it was raised?' (Ne'eman 2010: n.p.). Leaders of self-advocacy organisations of people with learning disabilities in Britain have also voiced concerns about serious funding difficulties (Pring 2016).

Several studies support the above claims of self-advocates and highlight the central role of funding. For example, without appropriate funding, disability organisations – including self-advocacy collectives – may not be able to operate or challenge the existing status quo (Balázs & Petri 2010; Chapman 2005). There is consensus that funding seriously influences the independence of self-advocacy organisations (Aspis 1997; Goodley & Ramcharan 2010; Pring 2016), because 'uncertain funding renders self-advocacy groups vulnerable to being used to serve the agendas of others' (Bigby 2015: 10). 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: 137). Notably, there is a dominance of articles from English-speaking countries and we know very little about how autistic self-advocates and self-advocates with an intellectual disability fund their advocacy outside Britain and the US.

This article appraises the role of funding in autistic self-advocacy and the self-advocacy by people with an intellectual disability. This inquiry builds on a previous study that found that disabled people's organisations, charities and the disability human rights movement as a whole only involves self-advocates with an intellectual disability and autistic self-advocates in token ways (Petri et al. 2017). It is our hypothesis that issues related to funding may partly explain this token involvement of self-advocates. Thus, this paper looks at how funding influences the position of self-advocates within the broader disability movement, including in disabled people's organisations, charities, human rights organisations, and so on. The present article builds on empirical data from two countries, the UK and Hungary therefore offers an important addition to previously published studies focusing almost exclusively on English-speaking countries.

## Why does money matter in self-advocacy?

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 impact both social movement organisations and their members. Leading social movement researcher della Porta notes that 'in fact, [social movement action] repertoires depend to a great extent on the cultural and material resources available to particular groups' (della Porta & Diani 2009: 183). 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: 66). Costs and benefits of participation may affect how individuals join social movements, for example, how much time they devote to participate in an action or whether they decide to join activism at all. Time itself can be costly, for instance when individuals spend time with unpaid protest activities instead of paid work.

Thus, the availability and distribution of resources within the disability movement influence strongly how groups operate. For example, it is possible that the three historically separated groups (Wehmeyer et al. 2000; Bylov 2006; Waltz 2013) in intellectual disability and autism advocacy, that is, 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.

Of course, when assessing funding issues, it is necessary to specify which types of collective or individual self-advocacy one would like to assess. The disability movement itself is composed of various organisations, formal and informal groups and individuals. Some (self-)advocates may join 'traditional', often smaller self-advocacy groups that are likely to be formed by both autistic people and people with intellectual disabilities, for example speak-up groups, cultural groups, and the like. Big organisations such as big charities in Britain or national umbrella organisations across Europe may also be an option for self-advocates, although most of these organisations are controlled by parents or professionals (Petri et al. 2017). A novel form of self-advocacy can also be identified: the community of autistic self-advocates who work together by various means, including online networks and other collectives (Dekker 1999; Bagatell 2010; Kapp 2020). Importantly, this type of self-advocacy often lacks the organisational background of formally established disability organisations and relies largely on individual self-advocates' voluntary, material, and other contributions.

When looking at the role of financial resources in self-advocacy, all these different forms of self-advocacy need to be assessed because 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 formal organisations or charities. Therefore, this paper asserts 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 funding of collective forms of advocacy (organisations and their funding, paid advocacy jobs) will be looked at.

This paper is part of a broader doctoral project that explored factors that hinder or support self-advocacy in the learning disability and autism movement (Petri 2018). The original doctoral study aimed at collecting data from two countries, the UK and Hungary, with the assumption that if similar barriers to self-advocacy are present in two countries with different historical and policy contexts, then those barriers may be of concern in many other countries as well. Although some differences were found – for example in how self-advocates can exercise their legal capacity under two different legal systems – the original study asserted that key barriers – including practices of disability organisations and lack of support to self-advocates (Petri 2019) – were the same in the UK and Hungary.

Given the lack of previous literature on self-advocacy and its complex relationship with financial resources, the question for this analysis, based on data collected as part of the mentioned doctoral study, is an exploratory one: 'How do financial resources influence the participation of self-advocates in different forms of disability advocacy?' Our aim is to appraise the influence of material resources.

## Research methods

To answer the above research question, this study includes 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 parents and professionals is similar to that of self-advocates'. In other words, if we want to know how money impacts self-advocates' position in the movement, we need to turn to other forms of intellectual 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.

Participants (M = 18; F = 25 – see **Table 1**) were recruited with the help of British and Hungarian disability organisations, the Tizard Centre (University of Kent), and through the researchers' own network. Snowball sampling was also used.

Participants had diverse backgrounds, for example:

- Professional advocates included social workers with an advocacy role; support workers to self-advocacy groups; community advocates; founders of disability advocacy organisations; leaders of legal clinics; disability human rights lawyers; leaders of autism or learning disability advocacy collectives.
- Parent advocates included activists at parents' organisations; leaders of national organisations representing families of autistic people or people with an intellectual disability; parents who work mostly alone as advocates and publish books/deliver workshops; founders of local parents' groups.
- Self-advocates included leaders and members of self-advocacy groups with an intellectual disability; autistic people advocating for themselves/others mostly in less formal ways; autistic people who do awareness-raising activities; founders/leaders of neurodiversity organisations; autistic people who use art to challenge traditional views about autism; autistic trainers specialised on autism.

Data collection was carried out in Hungary in late 2016 and in Britain in 2017. Participation was voluntary. All participants received written information and consent forms in their native language and also in an easy-to-read version in both languages. The research was approved by the University of Kent Tizard Centre Ethics Committee.

This study was originally part of a doctoral study (Petri 2018), thus, interviews and focus groups focussed on several issues related to the position of autistic people and people with an intellectual disability in the disability movement. Each interview and focus group included a discussion of the role financial resources. Depending on 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?'

Data analysis was carried out using thematic analysis (Braun & Clarke 2006). For the analysis, the first author read all interview and focus group transcripts several times and coded the texts by using NVIVO software. All interview

**Table 1:** Participants.

| Participants | UK | Hungary | Total |
|---|---|---|---|
| **Self-advocates with an intellectual disability** | 4 interviews (incl. one 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 intellectual 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 XXX country: N = 19 participants | Total in YYY country: N = 24 participants | **N = 43 participants** |

and focus groups transcripts were analysed in the original language (English or Hungarian) by the first author, and then codes and emerging themes were discussed extensively with co-authors. First, two major nodes were created 'financial resources' and 'self-advocacy as occupation', which was followed by consequent coding, discussions, and the identification of emerging themes.

## ANALYSIS: Money in Self-Advocacy – From Poverty to Paid Advocacy

All participants agreed that 'money' (as a shorthand used by participants for financial resources) is essential in exercising (self-)advocacy. There was consensus that funding was crucial for all types of advocacy. Participants also agreed that disability advocacy and self-advocacy can be seriously hindered when resources are not available. Data analysis found five emerging themes.

### *Theme 1: Costs of self-advocacy*

When asked about financial resources, many participants first 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 cost of support and the cost of travel. According to a senior professional advocate, support costs are often significant.

> 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 intellectual disability)

Another senior advocate agreed with this statement and stressed that although volunteers may be available, they cannot fully substitute paid support.

> 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. (British advocate in intellectual disability)

Support needs and costs of support are also significant in autistic self-advocacy. According to a Hungarian parent-advocate, autistic self-advocacy can be 'very expensive'. Here, specialist communication expertise is seen just 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-advocacy.

> I do think that the tools we can use to boost their [self-advocates'] collective advocacy, well, these are VERY expensive. (...) For example, when you want them [autistic 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)

Self-advocates in both countries pointed out that funding is necessary to cover the cost of support staff, transport and organising accessible meetings for people with intellectual disabilities.

> 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 an intellectual disability)

Transport costs were mentioned by several participants. Professional advocates working in rural areas in Britain saw travel costs as 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 self-advocates and parent-advocates was that many parents found financial issues similarly hindering. Families of disabled children often find it difficult to cover travel costs. According to a Hungarian human rights lawyer, lack of money prevents many 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 advocate in intellectual disability)

Other costs were also mentioned such as fees for legal expertise. Strategic litigation is one of the possible and potentially impactful ways disabled people can challenge oppressive policies – however, litigation may be very costly for those on low income.

> 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 [enough], 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 advocate in intellectual disability)

To conclude, the theme 'costs of advocacy' may include several potential barriers to practicing self-advocacy. Lack of funds to hire support staff may impede collective as well as individual self-advocacy. Transport costs often exclude those living in low-income households or in areas with under-developed and/or expensive transport. This means that a potential 'entry point' to practising self-advocacy, which is meeting peers, attending events or joining group activities may be impossible for many potential self-advocates on low income or for those living outside metropolitan areas. Consequently, those who want to join self-advocacy 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. This finding points at the next theme which is participants' views about those members of the disability movement *who are able to practice* (self-)advocacy: people 'who can afford it'.

***Theme 2: 'Those who can afford it'***

This theme concerns the income of those who practice advocacy and self-advocacy. The theme is labelled 'those who can afford it' because several participants stated that doing advocacy was a choice that ran against their financial interests. Although the theme was found to be relevant for all people who do advocacy or self-advocacy, it emerged predominantly from parents' statements. For example, a senior member of a known autism advocacy organisation stated that jobs offered at disability organisations usually offer low 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 decision whether one does advocacy or not may be influenced by basic personal needs. In a focus group discussion in Hungary, experienced parent-advocates cited the 'hierarchy of needs' scheme developed by Maslow (Maslow 1943). The 'hierarchy of needs' is a five-tier model of human needs, ranging from fundamental needs (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 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 rush to join advocacy (...), not until my own and my family's financial security is ensured! So only after it is [ensured] can I go and fight for others. It [advocacy] will always be secondary.
> Advocate 2: I agree. It is much, much harder when the family's [financial] situation is so dire that none of the parents has advocacy on their mind.
> (Hungarian parent-advocates in intellectual disability)

Parents also mentioned how advocating for their children may mean that they are working extra hours, often in evenings which may lead to burnout – prompting them to leave advocacy. This signals how the lack of financial resources may impact long-term commitments to advocacy. One advocate who had been leading a parents' organisation 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 (...) to 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)

Notably, financial rewards for 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 speaking at conferences and giving trainings for many years. Another participant, a professional advocate in England stated, 'you cannot make a living as an advocate'. Her view was supported by another 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 advocate in autism)

One autistic self-advocate in Hungary added '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.' Indeed, income was contextualised within the 'hierarchy of needs' by self-advocates as well. One self-advocate highlighted class divisions along Maslow's concept.

> 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. (UK autistic self-advocate)

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

When people start doing (self-)advocacy, they may be facing a choice: they can accept that advocacy generates low income, or they can choose to turn away from advocacy. Based on data presented above, the reality of present-day intellectual disability and autism advocacy is that only those people are most likely to engage with (self-)advocacy on a longer term who can supplement their salaries from other sources or those who have a solid financial background due to their social status. Thus, most people engaging in long-term and more formalised (self-)advocacy probably have secure financial background. People with lower income may be less likely to be found in advocacy because they 'cannot afford it'.

***Theme 3: Poverty – Those who cannot afford it***

This theme – linked directly to the previous one – draws attention to potential (self-)advocates who may be interested in joining the initiatives, but who never do because they live in poverty. Based on most participants' view both in Britain and in Hungary, one of the core issues in the context of funding advocacy is poverty, the daily experience of many disabled people and their families around Europe (European Disability Forum 1999.; Inclusion Europe and Inclusion International 2005). The view of one senior advocate seems dark but it explains why many disabled people never join advocacy.

> When you are struggling to put even 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 parent-advocate in autism)

A member of a Hungarian self-advocacy group summed 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[1] 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 an intellectual disability)

The daily reality of poverty was also noted by British participants. One advocate stated that many people do not access advocacy because they are unemployed and get little help even to leave their homes. The following participant framed their view about support needs in the context of much-debated intelligence quotient (IQ) scores, also reflecting on how everyday advocates may still employ medicalised views.

> 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

[1] The Order of Malta – referred to as 'Maltese' [in Hungarian '*Máltai*'] – runs a charity in Hungary that offers social services including shelters and food banks.

> an employment because they haven't got the support (…). 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 advocate in autism)

Poverty is clearly related to the lack of employment. Several autistic participants stated that although they were committed to find a job, they were unable to take on full-time employment which means they live on low income.

> 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)

The relationship between living on benefits and poverty was explained by another participant, who stated that the socio-economic system effectively excludes disabled people who need support.

> 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… (British advocate in intellectual disability)

In a focus group, Hungarian advocates discussed how poverty and access to advocacy intersect. The example of a pro bono legal aid clinic reveals that people in poverty find it difficult to access even free-of-charge advocacy services.

> I remember someone told me on the phone once '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 many people. (Hungarian advocate in intellectual disability)

Poverty is a major barrier for those wishing to advocate for themselves. Both in Britain and in Hungary, most autistic people and people with an intellectual disability find it difficult to access and exercise advocacy simply because they live in poverty.

***Theme 4: Independent income***

Another salient theme was the independent income of self-advocates. This theme is specific to autistic people and people with an intellectual disability because self-advocates in both countries stated that they wanted to achieve financial independence. A common view among self-advocates was that it did matter where their income came from. Many 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. (…) autistic people need to become their own advocates. So, they must get closer to employed positions [in the disability 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 be problematic because it 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)

A British self-advocate told her own story when she got a salary for her advocacy work at an organisation. Here, getting a salary instead of relying on welfare benefits was also related to becoming independent and moving out from a residential social service – a change she saw pivotal in her becoming a full-time self-advocate.

> 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 an intellectual disability)

The relationship between paid work and independence was further stressed by a professional advocate who recalled the example of a self-advocate with an intellectual disability who got 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)

Notably, paid positions for people with intellectual disabilities were seen exceptional by most participants. A self-advocate with an intellectual disability noted the lack of employment opportunities.

> 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 an intellectual disability)

All participants agreed that independent income can enable self-advocacy. Many self-advocates wish to find work that provides an independent income. Several participants said they did not want to rely on welfare benefits but got no support from to find and stay in jobs.

Importantly, jobs can be found within and without disability advocacy organisations. This leads to the final theme: self-advocacy in disability advocacy organisations rarely leads to a paid job.

***Theme 5: Self-advocacy is unpaid***

When participants were prompted to think about 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 was inappropriate or even silly. On the other hand, further statements provided rich data on how participants viewed self-advocacy as a source of income. This contradiction between first reactions and views expressed in words is very telling and can be explained by the theme 'self-advocacy is unpaid'. All professional advocates and most parent-advocates got various levels of remuneration for their advocacy work in both countries, however self-advocates rarely mentioned any income for their work. The views of a senior parent-advocate (and leader of an umbrella organisation) sums up the experience of many self-advocates: self-advocacy is seldom recognised as 'work'.

> 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 parent-advocate in autism)

In both countries, 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, an autistic self-advocate recalled one event where a leading autistic advocate did not get remunerated for his work.

> 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)

In both countries, several autistic participants did self-advocacy despite the fact that they do not get paid for it. One Hungarian 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, all self-advocate participants agreed that even unpaid self-advocacy – similarly to advocacy, as seen above – involves costs. Travel, support workers or other costs such as equipment were mentioned. One Hungarian 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 popular video blog on autism.

Although self-advocacy is often unpaid, sometimes it may generate some income, in the words of an autistic participant, a 'funny amount'. One previously quoted self-advocate noted 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 is a 'funny amount'. [smiles] But it already helps us a great deal.[2] (Hungarian autistic self-advocate)

The lack of payment for self-advocacy, however, was a debated topic. One self-advocate with an intellectual disability said it was unacceptable for her to work pro bono when others get paid for the same job.

[2] At the time of data collection, the crowd-funding site generated 41 USD per month.

> 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. Ten pounds vouchers and sometimes you don't get paid at all! (British self-advocate with an intellectual disability)

Showing that there was no consensus among self-advocates about whether they can accept unpaid advocacy, one participant recalled that although many self-advocates accept to work pro bono, other autistic people strongly oppose 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)

Notably, some professional advocates also stated it was problematic that self-advocates did not get paid for jobs others received remuneration for.

> 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)

Importantly, not all professional advocates thought self-advocates should get paid. They 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 large charity draws attention to divisions within the disability movement in how they see self-advocacy.

> 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 intellectual disability)

The decision to pay (or not pay) self-advocates is usually made by organisations who control resources: for example, NGOs and charities employ staff and decide about salaries their employees get. When asked about paid self-advocacy positions within organisations, a group of senior leaders of advocacy organisations (also 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 resources I mean they don't have the time and the money. If you hire someone to self-advocate then you need to support them, to help them get the competencies they need, and all this cost a lot of money. I don't think I know one single organisation in this country that can 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' practices and their allocation of resources. We found that most disability advocacy organisations – including human rights watchdogs – do not offer paid advocacy positions to autistic people or people with an intellectual disability. In Hungary, only one organisation employed one self-advocate with an intellectual disability on a regular basis. In the UK, two participants with an intellectual disability got 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. Outside organisations, only 'freelance' autistic self-advocates got some remuneration for their advocacy work – participants did not know about paid 'freelance' self-advocates with an intellectual disability.

## Conclusions – Funding and income as barriers

The most important finding is that the availability of financial resources is a major factor that influences strongly how self-advocates participate in the disability movement.

Self-advocacy itself requires financial resources. Running self-advocacy groups involves costs such as salaries of support staff, transport costs, and costs of venues. 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 for disabled people (Eide & Ingstad 2011). Those who live in poverty can rarely devote time and resources to do advocacy or even to access advocacy services. This study shows that self-advocates from low-income backgrounds find it very hard to join collective forms of self-advocacy or even to exercise self-advocacy on their own.

In the context of funding self-advocacy, organisations pay a central role. However, self-advocates rarely get paid for their work in disability organisations. Thus, some self-advocates follow individual pathways and try to generate income from 'freelance' types of (self)-advocacy, for example by establishing themselves as trainers or consultants.

Although employment can give self-advocates an independent income which was seen as a crucial factor that enables self-advocacy, most self-advocates struggle to find jobs. People with an intellectual disability and autistic people face a low level of employment across Europe (ANED 2018) partly due to lack reasonable adaptations at workplaces (Moody et al. 2017). Based on findings, autistic people and people with an intellectual disability do not get much better opportunities to work in salaried jobs in the disability movement than they get outside the movement. The fact that parents and other non-disabled participants acknowledged this finding reasserts that practices of disability organisations do disadvantage self-advocates, and this is far from being a claim made only by self-advocates – it is widely known across the movement in both countries. In fact, findings show that most disability organisations in both countries – similar to most civil society organisations in general (Todd & Munro 2021) – maintain systematic barriers that exclude self-advocates from paid positions in the movement. Leadership decisions, organisational culture, lack of reasonable adjustments, the allocation of funding, and stigma can all be part of these barriers. Further studies should explore such organisational barriers.

Organisational practices today result in a situation where self-advocates are seen more as passive recipients or clients of advocacy services even when they actively contribute to projects and the running of collectives or organisations. This proposes a serious problem that runs against 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 for.

The two main types of self-advocacy (self-advocacy within and outside organisations) offer different risks and opportunities. While organisations control certain level of funding, and can allocate salaries to self-advocates, individual (self-)advocates need to look for funding themselves. This was seen by participants to be difficult but possible; several participants in both countries had experience in fund-raising for extra-organisational (self-)advocacy. However, paid, extra-organisational self-advocacy is rare. Findings indicate that autistic people and people with an intellectual disability have very limited opportunities to raise enough income as self-employed (self-)advocates.

Why people still choose to do extra-organisational forms of (self-)advocacy? One reason is the lack of paid positions for self-advocates in disability organisations. Previous studies also found that self-advocates working within organisations are often tokenised and excluded from decision-making (Petri et al. 2017), thus extra-organisational self-advocacy may seem even more attractive to those critical with disability organisations.

To conclude, several factors were identified that may impede self-advocacy. Members of the following groups probably have a much lower participation in self-advocacy, or their self-advocacy is seriously 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; and
- People whose working hours in employment do not allow them to engage with self-advocacy.

Maslow's hierarchy of needs (Maslow 1943) was cited by participants as a relevant predictor of who 'can' engage with advocacy – thus Maslow's pyramid may also serve as a heuristic tool to understand why some people engage in self-advocacy and others do not. For example, participants suggested that only those join long-term forms of (self-)advocacy who have a certain, secure financial background. Indeed, social class or household income – much-overlooked in research on disability advocacy – may be a strong predictor of who can join or get leadership positions in present-day organised disability advocacy.

Data showed that societal barriers such as poverty or lack of employment are exacerbated by practices of disability organisations. The distribution of resources in the autism and intellectual disability movement clearly favours non-disabled people (professionals or in some cases parents), although salaries of even paid advocates are seen to be low. In fact, it seems a standard procedure in many disability organisations that self-advocates are expected to work for free. Internal hierarchies within the disability movement (i.e., Goodley 2012; Petri et al. 2017; Petri et al. 2020) are strongly influenced and maintained by the availability of funding (Meyers 2019) and resources allocation to self-advocates. Findings suggest that many disability organisations that claim to be fighting for human rights, equality and emancipation are also maintaining or contributing to economic inequalities.

## Additional File

The additional file for this article can be found as follows:

- **Easy read summary.** Easy reader version of the article. DOI: https://doi.org/10.16993/sjdr.738.s1

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GP received the Tizard Scholarship during the study. All other authors have no competing interests.

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