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Reflections on the value of autistic participation in a tri-national teacher-training project through discourses of acceptance, othering and power

Rebecca Wood and Damian Milton

The Transform Autism Education (TAE) project is a tri-national teacher training scheme involving Greece, Italy and the UK, whose purpose is to set up training projects to facilitate the educational inclusion of autistic children. Running over three years from 2014 to 2017, the involvement of autistic participants has been the source of some discussion. Here, TAE team members Wood and Milton reflect on narratives of participation, acceptance and struggle which emerged during a workshop they ran in Greece. Derived from 11 non-autistic and two autistic participants, and analysed via discourse analysis, these stories suggest a high value placed on autistic participation by non-autistic TAE team members, but an unwitting tendency to 'other' autistic people and a lack of awareness of the power differential. Meanwhile, as the autistic team members describe how educational and social participation can be achieved, the implications for autism education researchers and practitioners are discussed.

Key words: autistic participation, discourse analysis, teacher training, inclusion

Introduction

The complexities of a project involving multiple participants from diverse professional contexts and different countries and speaking different languages, and how these interweave with issues of autistic participation, have been explored by Milton and Wood (2017). We discussed how, in the Transform Autism Education (TAE) teacher training project, involving practitioners, therapists and academics from Greece, Italy and the UK, there has been a need for translators and interpreters to enable the participation of people of diverse nationalities in order to co-operatively produce the training materials aimed at assisting the inclusion of autistic children in primary schools. Meanwhile, however, there has been an additional requirement to facilitate the involvement of autistic people through flexible modes of participation and, in some senses, 'translation', provided by autistic scholar Milton and other autistic contributors. In addition, the TAE project, which is founded on the model of Communities of Practice (CoP) (Wenger, 1998; Wenger-Trayner, 2015), means that issues of 'community' and 'participation' are particularly apposite in a complex, multi-lingual team involving non-autistic and autistic people, and focused on improving educational inclusion. This leads us to reflect on how the TAE team perceives the participation of autistic people in its research and practice community, and to consider the lessons that can be drawn from this for future teacher training endeavours in the context of autism.

Methodology

During a workshop with the TAE team (which included two autistic participants) in Greece in 2017, we delved into questions of 'community' and 'participation' using a combination of visual, audio-visual and discussion-based methods. This culminated in the production of individual 'stories' using a model adapted from Wenger et al. (2011), which permits the merit of 'the learning enabled by community involvement and networking' to be ascertained through, inter alia, the development of 'value creation' narratives. The workshop itself was part of a week of meetings, training exercises and development events in connection with the TAE project, and the resultant stories are the focus of this analysis and the ensuing discussion.

The workshop participants consisted of academic researchers, autism practitioners, psychologists, special education teachers and students, all of whom are broadly TAE team members. The two autistic participants are both university students in Greece. The rest of the participants were either tenured university academics, senior special education managers, teachers (including one headteacher), university students or psychologists. Participants' stories evolved from the discussions that took place during the workshop, following which team members were provided with questions relating to their experiences of autistic participation in work, study or research as an optional guide or a prompt. Wood devised the questions for the non-autistic participants, which were adapted by Milton for the autistic participants. Importantly, the production of stories was both voluntary and anonymised: not all workshop participants opted to write a story, and in the event 13 – roughly half of the group – chose to do so. Further, and in keeping with the theme of the workshop and of this analysis, we distinguish only between the autistic and non-autistic participants.

This discussion, focusing on the stories produced by the TAE team members, employs discourse analysis, which broadly consists of 'a set of methods and theories for investigating language in use and language in social contexts' (Wetherell et al., 2001). Derived from an interpretative paradigm, discourse analysis is predicated on the notion that words and phrases 'do not come ready packaged with a specific delimited meaning that a researcher can be sure to know as if they were fixed and self-contained' (Parker & Bolton Discourse Network, 1999), but rather that narratives require analysis and interpretation in order to ascertain the ideas that are rooted within them. Indeed, for Taylor (2001; original emphasis), 'language is constitutive: it is the site where meanings are created and changed', and so it is the role of the researcher to 'investigate meaning and significance' (Taylor, 2001) and how these are fashioned within discourses. Therefore, in this account, our attention is drawn to the meanings which evolve from and are created within the discourses themselves. Specific information about the participants and their work, for example, are provided within the stories and are not supplied extraneously.

In addition, and crucially in the context of this discussion, discourse analysis permits the 'intimate connections between meaning, power and language' (Parker & Bolton Discourse Network, 1999) to be explored, because language is itself a form of power (Grue, 2015), which 'creates what it refers to' (Taylor, 2001). Indeed, it is through language that people are categorised, 'or separated out as different', and either assigned or denied value (Taylor, 2001). According to Grue (2015) therefore, the purpose of discourse analysis is not only to set out how different phenomena are represented, 'but to tease out the implications of such constructions and representations', an undertaking of particular relevance in the field of disability, as the researcher must 'keep looking for the ways in which disability – and disablement – is constructed, administrated, and policed through the socially and bureaucratically embedded use of language' (Grue, 2015).

Our approach was to read the stories separately, initially identifying 'key words in context' (Wetherell et al., 2001) within individual stories. This was followed by a broader analysis where we ascertained concepts, themes and contradictions, as well as possible 'systems of meaning' (Parker & Bolton Discourse Network, 1999) embedded within and across the participants' stories. To this extent, there is an overlap between our approach and thematic analysis (Braun & Clarke, 2006), sometimes referred to as 'thematic DA', whereby 'broader assumptions, structures and/or meanings are theorized as underpinning what is actually articulated in the data' (Braun & Clarke, 2006). We subsequently compared, shared and honed our ideas through discussion, a process that was followed by a second wave of individual analysis and further discussion, leading to the five broad categories which will now be described and discussed.

The participants and their stories, which in this analysis are written in English, are identified as follows:

- P1 and P2: autistic Greek participants;
- P3–P11: non-autistic English, Greek and Italian participants.

The accounts of P1 and P2 were translated from Greek by TAE members Katingo Hadjipateras Giannoulis and Lila Kossyvaki. Although several TAE team members are fluent in English and some are bilingual, the fact that not all stories were written in participants' native tongue, and some are in translation form only, needs to be factored into any consideration of the language used and presents a limitation to this discussion.

Participation

Nearly all of the non-autistic participants expressed a strong appreciation of the value of input from autistic participants generally in the autism field and in the TAE teacher training project in particular. P4, for example, referred to the 'major impact' an autistic person had once had on her autism education work, while P6 said it had been 'amazing' to encounter a high number of autistic contributors at a previous TAE gathering. For P9, involving autistic people in an autism teacher training project had been 'valuable', since they provided 'a unique insight'. These views were sometimes expressed in emotive terms, with P8 stating that she was 'happy and proud' to be involving autistic people in the TAE, while P4 acknowledged the 'powerful, ground-breaking delivery' of an autistic speaker, leading to changes in her approach to educational inclusion. In addition, P2 referred to the importance of recognising the diversity of autistic people, their 'uniqueness', a view also expressed by some of the non-autistic participants as being a key component of autistic participation generally. Therefore, while a high value was placed on the input of autistic people into teacher training programmes focused on improving educational inclusion, blanket, generalised approaches to facilitating their participation were felt to be unhelpful.

Difficulties and struggle

Notwithstanding the broad appreciation of the worth of autistic input into autism-related projects and study, some stories revealed conflicts and struggles within this process. This was particularly evident with P3, who described the problems she experienced with a young autistic man to whom she had intended to provide therapeutic support. Although 'excited' prior to their first meeting, P3 described herself as 'a bit stressed' too, as she considered 'how to accommodate' him and

subsequently, as the meeting started to degenerate, 'make adjustments' to try to improve matters. Similarly, P10 referred to 'the difficulties and issues' faced by a group of autistic people she was observing in a therapeutic context. In addition, P11 raised the problem of the sensory impact of lots of talking in a room with poor acoustics, and asserted that this would make it 'difficult' for autistic people to participate and engage.

Meanwhile, P1 referred to several 'difficulties' – a word he uses four times in an account of under 200 words – he had experienced as a university student resulting from a lack of knowledge about autism, and P2 decried the fact that a family member had expected her to change – 'suddenly become sociable, make eye contact . . . and stop stereotypical movements' – when she started seeing a psychologist. While these examples contrast starkly with other accounts from non-autistic contributors which present an idealised, problem-free concept of autistic participation, those from P1, P2 and P3, in particular, reveal difficulties and struggle in engagement between autistic and non-autistic people.

Crucially, these problems emerged within a support or therapeutic context, where P1 was hoping to find 'help', for example, and P3 was aiming to provide input to an autistic man who was 'seeking help'. Further, while P3's autistic client accused her of only focusing on his 'difficulties', she concludes that the breakdown of their relationship results from the fact that he 'misinterpreted social intentions and behaviours'. Similarly, the setting for P10's story is a 'social group' for autistic people, implying they required therapy or remediation in this area. These examples suggest that if autistic participation is predicated on a therapeutic model, with the autistic person expected to adopt the role of damaged or impaired individual, difficulties in engagement may well arise. Indeed, when problems are considered to be rooted in the putative social dysfunctions of autistic people, then their participation and membership of the community is not only an unequal one, but necessarily conditional upon them being successfully treated by the non-autistic therapist who is not deemed to be similarly impaired. By contrast, however, P5 considered that a key message from the workshop which had preceded the story-writing was that we are all 'imperfect humans', implying that we are all, to a greater or lesser extent, impaired.

Listening to the others

P4 asserted that she and her work colleagues, who deal with educational inclusion for autistic children, 'took a big step' following a presentation from an autistic person. P6 also listed several changes to her approach to autism education research after hearing about the 'views and experiences' of autistic people at a TAE meeting in 2016, stating that 'we cannot discuss' autism research and 'good practice' without involving autistic people. For P7, the workshop which preceded the story-writing had served to open 'our minds', while P8 averred that 'the only way we can truly collaborate and create something meaningful that will bring change' is by learning from autistic people. For P5, to engage with autistic people in participatory exercises is to be 're-educated', meaning all become 'better people' and 'develop better empathy, deeper understanding (and) learn to listen better' – the repetition of the word 'better' underscoring the restitutive role of such an arrangement. In addition, P5 stated that participants' comments during the workshop suggested there was 'no set of rules and guidelines' for autistic people, especially as P1 and P2 had both responded differently to the visual and audio-visual materials employed.

However, some accounts displayed an uncomfortable alliance between acknowledging the potential particularity of autistic dispositions and a tendency to 'other' autistic people, including Milton, who ran the workshop jointly with Wood. 'Othering' has been described as a situation or narrative in which 'the normal' and 'the pathological' are separated (Hughes, 2009), where some are defined as 'abnormal' (Milton, 2012), potentially leading to 'stigma and bullying' (Milton & Sims, 2016). In these stories, and notwithstanding the broadly positive attitudes towards autistic participation, there are references to what 'THEY' – autistic people – as opposed to what 'WE' – non-autistic people – think (P8, emphasis in original story), or to how Milton's 'mind works' (P3), thus framing him as an 'exotic other' (Arnold, 2013). Indeed, while there is a possible contradiction between recognising the diversity of the autistic community, which is suggested in some stories, and a propensity to 'other' autistic people on occasion, this is reinforced further by an assumption that the 'we' category of non-autistic people is somehow heterogeneous. For example, P5 asserts that 'we are all people with a social science background' – which was not the case – while P8 referred to 'the autistic point of view', contrasting this with the perspective of 'neurotypicals'. In addition, P6 expressed a pleasant surprise that autistic people might be 'happy to participate' or 'happy to share' their views and experiences, implying not only that autistic people might typically be unwilling to do so, but that, by contrast, non-autistic people are intrinsically pre-disposed to public divulgence. In fact, P1 stated that it took some effort for him to inform his university about his Asperger's diagnosis, because this is an issue he finds 'very hard to talk about', suggesting that for him at least, it is not a question of volition.

Ceding power

While the stories from the non-autistic participants suggested a strong desire to involve autistic people in their work, research and practice, there appeared to be perhaps unconscious limits to their willingness to shift the power from them and their institutions to the autistic individuals. P10, for example, reveals an emphasis on her commanding role within a therapy session with a group of autistic people, as she was 'supervising' another professional, who had overall 'responsibility' for the group which she was 'running and managing'. In addition, P4 asserted that an autistic person was 'offered . . . the opportunity' to give a presentation at an autism education and support conference, making it clear that the power lay within the gift of P4's organisation. Indeed, and notwithstanding clear statements about the benefit of this autistic input, such a comment implies that this was an important opportunity offered to the autistic person, rather than the other way around. Similarly, P6 stated that some autistic people had been 'invited to speak', and not, for example, 'asked' or 'requested', a framing which would more fruitfully suggest that the benefits are for the audience, rather than the autistic speakers. Further, P6 considers that a future aim is to 'provide more opportunities' for autistic people to take part in conferences, for example, a notion predicated on the assumption that they are incapable of creating such opportunities themselves. In addition, P8, who expressed fulsome views about the importance of autistic participation, stated that it is important 'to help and allow' autistic people to express their views, and aired the wish that they might 'inspire others' to do likewise. Indeed, P8 went further to propose that situations where 'autistic people participate as equals' would be 'wonderful', an assertion reminiscent of campaigns for women's suffrage, for example. Therefore, in these aspects of the narratives, non-autistic contributors' views about autistic participation are intertwined with the notion that they, the non-autistic people, hold the power, which permits them to provide opportunities to less potent others.

Understanding, acceptance and success

If the narratives from the non-autistic participants emphasised the importance of autistic participation, but sometimes showed a tendency to 'other' autistic people and to underscore an unequal power balance, those from the autistic participants centred on knowledge, acceptance and well-being, particularly within their education settings, and how this might be achieved. For P1, the various 'difficulties' he experienced at university were due to there being 'no knowledge' among some of the staff about how he could be helped to 'handle the situation'. For him, it is very important that university staff are 'informed' about autism by a 'specialised professional', meaning that rather than 'difficulties', he and others like him will experience 'less distress' and be able to complete their studies 'with success'. Meanwhile, P2 explained how she is made to 'feel welcome' by a specific friend who lets her talk 'endlessly' about her particular interests, and who has never 'made a negative comment' about the fact that she is autistic. This contrasts with a close family member who she feels 'does not accept (nor) understand' her as an autistic individual. Furthermore, unlike some of the accounts from non-autistic participants which were predicated on the notion that access to the community depends on a reduction of autistic social impairments, not being expected to change is a key issue for P2. Indeed, while P1 finds it difficult to talk about autism, P2 emphasises the importance of being able to talk freely, of being listened to and of not being expected to alter her particular autistic disposition. Importantly, such an attitude of acceptance and 'respect' makes it easier for her to 'be more sociable'.

P2 also recounts an activity where she made a puppet as part of her university course, during which she realised that her ability to work quickly and concentrate intensely was a considerable advantage in the task. During the activity, P2 became aware not only of how much she enjoys 'doing crafts with (her) own hands', but that her imagination played an important role in its success. The positive language she employs in this description – in which she uses terms such as 'creative', 'good', 'excited' and 'like' – contrast with the vocabulary of difficulty and struggle discussed earlier, serving as a key indicator as to how these issues might be remediated. Further, the intense concentration she describes is highly evocative of what has been termed as the 'monotropic' thinking and learning style of autistic people (Murray et al., 2005; Lawson, 2010), and has also been associated with a deep sense of well-being, or 'flow states' (McDonnell & Milton, 2014). In addition, while it is implied that a female family member had criticised the way she dressed and expected her to alter what she wore, P2 found considerable satisfaction in creating a puppet of a different gender, which 'looked a lot like Mozart'. In addition, during this activity, P2 'was not doing any social ... was just getting on with the job', implying that being engrossed in an activity – monotropism – necessarily means a lesser focus on social interactions. Nevertheless, P2 found that by playing with the puppet with her fellow students, she was able to express certain sides of her personality, such as being 'strict', which would not ordinarily be 'socially accepted'. Indeed, while some accounts from non-autistic participants showed a tendency to 'other' autistic people, P2 finds that it is only by channelling her personality into another, fabricated being that she is able to vent certain aspects of her character and acquire social acceptance. Consequently, even though P2 was 'not doing any social' during the puppet-making exercise, the ability to engage with the activity in a manner which accorded with her learning and thinking style provided her with a social connection which appears not only effortless, but is devoid of the 'difficulties' which emerged within the therapeutic and support contexts described earlier.

Discussion

Notwithstanding the high value placed on autistic participation by non-autistic TAE team members, it is arguably the small number of stories revealing difficulties and struggle that are more instructive about how good intentions – to increase the participation of autistic people in education and research – come into conflict with the reality of potential disconnections and misunderstandings. Indeed, the candour of these participants is to be applauded, as such descriptions are revealingly evocative of the ‘double empathy’ problem – ‘a disjuncture in reciprocity between two differently disposed social actors’ – as framed by Milton (2012). P3, for example, describes the breakdown of a rapport between therapist and client which centred on her belief that an autistic man was socially impaired, while he became furious at the implications of this assumption, rendering the various preparations, adjustments and planning undertaken by the therapist entirely futile. Similarly, P1 struggled to find academic staff who would understand his ‘difficulties’, delaying and frustrating his wish to make a success of his university education. These accounts not only challenge the notion that autistic people might be ‘weak empathizers’ (Smith, 2009), but suggest also that negative assumptions made on the basis of the label of autism can sow the seeds for mutual incomprehension. Muskett (2016, p. 306), for example, asserts the following:

‘I argue that to construct certain language and communication behaviours as merely signs of ASD may obfuscate personal, contextual, experiential or social meanings for the phenomena in question, in favour of upholding a persisting medical analogy that appears logically contestable’.

Moreover, the implications for educational practices concerning autistic children and adults – which still depend on a therapeutic model (Jordan, 2005) – are clear, given that the ‘relentlessly deficit-oriented history of special education’ (Thomas, 2012) has done little to further inclusive practices. Indeed, standards for inclusion in the special education field generally create ‘a problem and a spectacle of difference’ (Allan, 2008) for educators to manage. Furthermore, these issues are akin to the problem of ‘othering’ discussed earlier, whereby autistic people might be ‘invoked with great passion and pomp’, but remain ‘off-stage characters’ (Broderick and Ne’eman, 2008). This is reminiscent of the ‘social group’ referred to by P10, who we perceive dimly at the bottom of the hierarchy of lead practitioner, supervising a psychologist, who in turn is ‘running and managing’ the autistic people, about whom we are provided with no details whatever. Indeed, such an alignment might result in ‘erasures and absences’ or ‘the disappearance of the Other’ (Allan, 2010) entirely from educational policies and practices, for example, with autistic people ‘not fit to offer any lines of actual dialogue’ (Broderick and Ne’eman, 2008) or be meaningful actors in restitutive change.

In addition, these narratives reveal the sway that institutions – educational, medical and administrative – hold over individuals, as non-autistic participants, who are ensconced within them, discuss the ways in which autistic people might be invited in. Such a positioning serves as a reminder of how discourses about disability might ‘produce and sustain discourses of power’ (Liasidou, 2012), which ultimately dictate ‘who and what gets valued, and who and what gets marginalized’ (Devlin & Pothier, 2006). Indeed, from a Foucauldian perspective, language itself, and the ‘truths’ that it creates, can become crystallised into ‘institutions of authority’ (Downing, 2008), perpetuating tensions and confusions which cannot be resolved easily (Rioux & Valentine, 2006). Consequently, the language about inclusion can in fact perpetuate exclusion (Liasidou, 2012), while ‘deficit discourses’ in educational environments can have ‘debilitating effects’ on the lives of those young people to whom they are applied, ‘creating negative, damaging and often incontestable, singular identities’ (Humphrey, 2014). In these respects, special educational needs discourses can become drivers of educational exclusion and long-term ostracism, an issue reflective of the Foucauldian view

of how 'apparent humanitarianism of reason' might disguise 'techniques of oppression and marginalisation' (Downing, 2008).

Two of the stories from non-autistic participants portray a therapeutic relationship, with the story-teller in the commanding role of the expert, and the autistic people as much less potent, impaired others. In contrast, however, the narratives from P1 and P2 indicate that rather than therapeutic interventions which seek to remediate and repair, being understood, and provided with the circumstances in which they can learn as the people they are, is ultimately more enabling and fruitful. This suggests that the unequal power balance inherent in the therapist/ client model needs to be re-evaluated, with strategies provided by Personal Construct Psychology (PCP) suggested by Moran (2006) and Williams and Hanke (2007) offering a more considerate space to negotiate roles and agency in the context of autistic people of all ages. Approaches based on PCP place at the centre of analysis an individual's own use of language and the meanings they attach to their own personal constructs: the goal is to explore reciprocal understandings and what can be learnt from those processes, rather than a top-down, 'therapist knows best' model. Notions of mutuality and respectful practice within therapeutic and support contexts for autistic people are also discussed in Chown (2016).

In addition, there are early indications that peer-to-peer mentoring schemes such as AuVision (Searle et al., 2016) and the Cygnet Project (Martin, 2017) can be more effective in assisting autistic university students than typical models of support, which exclude autistic expertise. Furthermore, the unhappy status quo described by P3 may result from the failure on the part of the well-intentioned therapist to be cognisant of 'the new forms of sociality' and 'the role that autism can play in forming new social identities' (Grinker, 2015), which a medicalised conceptualisation of autism, and the emphasis it places on social dysfunction, necessarily prevents. Here, the autistic person is repositioned as an individual within a cultural framework, helping to redefine our very understandings of community:

'The concept of culture in autism research is thus useful not just for characterizing a community's system of meanings that influence how autism is identified, managed, experienced, etc., but for showing that those meanings are constructed and can therefore be changed'.

(Grinker, 2015, p. 349)

Conclusion

According to Wenger et al. (2011), a community is formed, in part, by a 'collective narrative around a practice', and while that narrative might be 'contested' or even 'contentious', learning can only take place if there is a joint commitment among the members of a CoP to create a shared account of its values. Meanwhile Grue (2015) considers that researchers must ask 'what social, moral and political arguments lie implicit in different discourses' in order to be able to realise the sort of change emphasised as necessary by P5, for example. The brief collection of stories discussed here shows a clear allegiance among non-autistic TAE team members to the notion of autistic participation, with some outlining – in highly emotive terms at times – how engagement with autistic people had impacted positively on their education, work and research practices, or would do so in the future. Indeed, P8 in particular underscored the point that collaboration, change and the creation of 'something meaningful' would only be possible with such engagement, a notion reminiscent of the 'reframing strategies, goals, as well as values' which Wenger et al. (2011) describe as the ultimate indicator of 'value creation' within a CoP.

These stories imply that notwithstanding the high value placed on the input of autistic people into training programmes that focus on increasing the educational inclusion of autistic children, their very participation could be hindered if it is embedded within an unequal power balance. Similarly, practices rooted in an assumption of autistic dysfunction may founder because of those attitudes, while, on the other hand, a recognition and accommodation of autistic dispositions and expertise offers a potential gateway to success. Indeed, Nind (2008) outlines how researchers must consider shifting the power imbalance in the disability field, suggesting that it is more fruitful to conduct research 'with' rather than 'on' people with communication difficulties, for example, and arguing that participatory methods should be considered at all stages of the research process (Nind, 2011). In these ways, and while remaining cognisant of the limitations of an analysis of brief data based on a method that is sometimes accused of lacking 'ecological validity' (Parker & Bolton Discourse Network, 1999), we have offered suggestions of how such improvements might be achieved, potentially providing 'new metrics for performance' and a 'new definition of success' (Wenger et al., 2011) in education and research communities involving non-autistic and autistic people.

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