

‘An Association for All’—Notions of the Meaning of Autistic Self-Advocacy Politics within a Parent-Dominated Autistic Movement

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ABSTRACT

In this paper, we seek to explore the tensions between advocacy and self advocacy autistic movements in a Swedish context with a special focus on the meanings that enable the production of particular understandings of autism and the autistic subject. Drawing on articles written for the Swedish advocacy magazine Empowerment written for and by people with autism, the discourse analysis explores two competing discourses: a reformist and a radical. The reformist discourse underlines a goal of (political) representation expressed in Empowerment. It may be understood as an important part of producing a legitimate autistic political subject—positioned as a full member, with a full membership—within a parent-dominated autistic advocacy movement. The reformist discourse can be viewed as a result of a negotiation, where full membership is conditioned on the parents’ terms and granted on specific terms. These include working together (neuro-inclusively), advocacy based on interest rather than identity/position as a specific target/member group, agreement upon a definition of autism as a disability (a deficit) a person has rather than an identity. In relation to this, an alternative legitimate autistic subject is produced through invoking the counter-hegemonic radical discourse. Such a narrative produces the ‘Asperger’ or ‘Aspie’. Here, the ‘full membership’ refers to a sense of identification with sense of belonging to and being at home with other people with autism. It contains a certain amount of autistic solidarity within the group of adults with autism. Copyright © 2014 John Wiley & Sons, Ltd.

Key words: self-advocacy; autism; identity; Asperger syndrome; parents

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INTRODUCTION

We want to gather the country's Aspergers further in an organization of our own that we feel that we ourselves have created and therefore for our own actions. With regard to our questions there have so far only been parent organizations in which we with a diagnosis of our own has been around on the fly, but most often dominated by parents and their often largely totally different perspective. (Press release, Organized Aspergers, 02-04-2009)

Parent-led support groups and advocacy have become an increasingly common aspect of public discourse for children with a range of health and educational needs. In this paper we explore tensions between advocates and self-advocates within a parent-led movement for people with autism. We, and others, have argued that there is an ambivalent relationship between advocates (mostly parents of children with autism) and self-advocates within autistic politics, what Orsini has referred to as 'autism wars' (Orsini, 2009, see also Chamak, 2008); the struggle between different groups 'within' the movement for rights of interpretation. Orsini (2009) makes a distinction between the 'autistic movement' and the 'autism movement'. Orsini refers to the 'autistic movement' as 'the efforts of activists to create a positive identity for autistic people using, albeit not exclusively, a disability rights frame.' (p.115). This movement includes people who self-identify as autistic as well as non-autistic sympathetic others supporting the general goals of the movement. Orsini refers to the 'autism movement' as 'activists or advocates more interested in pressing for policy change around the treatment for autism and concern with its causes' (p.115).

In the past 20 years lay explanations of autism (including people speaking about their experiences of autism) are often equated with the parental or families' perspectives (see for example Chamak, 2008; Gray, 1994). This has been noted, for example, in the UK during 2002–2003 where parental discourse around the links between MMR and autism was given significant coverage in public media debates. At this time, parental voices were positioned against the established scientific community and (in particular contexts) seen as the authority for understanding the potential link between MMR and autism (O'Dell & Brownlow, 2005; Wolff, 2004).

Whilst the more dominating medical or 'professional' discourse of autism has been contested (at times) by the 'lay' discourse of parents and other relatives, both discourses position autism and the child with autism as problematic and ascribe to a deficit-focussed view of autism. The very negative construction of autism was evident in the parental discourse mobilised around MMR, where the vaccine was seen to have 'damaged' children (O'Dell & Brownlow, 2005). The construction is also mobilised in autism movements where the dominant medical construction of autism is accepted unproblematically (see for example Farrugia, 2009; Goin-Kochel & Myers, 2005; Gray, 1994; Orsini, 2009; Orsini & Smith 2010). Whilst parents are typically marginalised in the discourse of public policy, they have made important contributions to lay constructions of autism.

There is however a growing alternative construction of autism coming from adults with autism, which seeks to challenge the dominant construction of autism as deficit. The framing of autism as a form of 'neurodiversity' permits self-advocates to draw on a conceptualisation of the strengths and possibilities of being autistic. Armstrong (2010) proposes that through drawing on the ideas of neurodiversity a more balanced view of autism can be achieved, one that does not emphasise 'disorder' but which instead places value on neurological difference. This counter discourse of diversity is beginning to offer a significant

challenge to the dominance of a deficit construction of autism and to develop new forms of self-advocacy.

The positioning of a 'diversity' discourse is firmly within the scope of *self-advocacy* movements rather than *advocacy* movements. We argue in this paper that the distinction between the two advocacy movements is characterised by the dominant voices within the movements, rather than with essentially different goals. We will therefore refer to self-advocacy versus advocacy movements, rather than autistic/autism movements. *Self-advocacy* movements are dominated and led by individuals who identify with a particular label, in this case autism. *Advocacy* movements are organisations that seek to *speak for* people who identify with a label, such as autism. Parents, professionals or other individuals who share a sense of social justice with the individuals labelled, but speak for such individuals may therefore lead such advocacy movements. The differences between the two movements are seldom fixed. Rather, movements are often characterised by a more or less tense cooperation between both advocates and self-advocates within a mixed movement. What follows is therefore an exploration of the tensions *within* a movement characterised by both self-advocacy and advocacy, drawing on examples from a movement within the field of autism. However, we expect that some of the issues raised will not be specific to autism, and commentaries may apply to a wider range of both separatist and mixed movements.

Autistic self-advocacy: an overview

Ward and Meyer (1999) note that the autistic self-advocacy movement initially emerged as a civil rights movement. People with autism were campaigning against the treatment that they received within society and challenging the portrayal of them as child-like and unable to make competent decisions of their own. Whilst Ward and Meyer trace the development of the self-advocacy movement to Sweden and the work of Benget Nirje (1972) and his normalisation principle, similar developments are evident in other countries (Chamak, 2008). The normalisation principle is highly influential in contemporary Swedish disability discourse. Contemporary Swedish disability policy stresses that 'everyone is of equal value and has equal rights' (2009). Policies such as de-institutionalisation, normalisation, inclusion and participation have affected the everyday way of life of those with developmental disabilities (Lövgren, 2013). However, in tracing the history of autistic self-advocacy, Ward and Meyer highlight that the take up of large-scale autistic self-advocacy did not formally begin until the work of the Swedish researchers Carina Gillberg and Christopher Gillberg (1989) who published the diagnostic criteria of autism. Through translation into Swedish, publishing and circulation by the parental dominated autism advocacy organisation, the Swedish National Society of Autism, the criteria have been widely circulated in Sweden. Ward and Meyer argue that it is through the availability of the criteria that people with autism were able to make sense of themselves. This sense making was enabled through the position of professional medicalised diagnosis and through drawing on more empowering models of disability such as the social model of disability, with the distinction between disability and impairment. Such a framework for understanding provided by the social model of disability enables the construction of impairment as not necessarily disabling unless the wider social context constructs this as a disability (see for example Oliver 2013). Such a framework of diagnostic criteria and a model for

understanding provided a focus around which an organised self-advocacy could gain momentum.

Such possibilities for new ways of thinking and understanding led to the organisation of like-minded individuals into groups (Ward & Meyer, 1999). Advocacy organisations were the first to emerge; self-advocacy groups (i.e. those run by people who identified themselves as autistic) were less evident at this point (Ortega 2009; Ward & Meyer). Broderick and Ne'eman (2008) note that it was advocacy organisations that enabled parent groups to reach the wider public with their agenda. These groups typically draw on a deficit view of autism as something to be 'cured', 'fixed' and 'eliminated'. In contrast the self-advocacy movement has largely drawn on the discourse of neurodiversity (Ortega 2009), highlighting neurological difference rather than deficit, challenging the assumptions inherent within a deficit view of autism, seen for example in theory of mind (Brownlow & O'Dell, 2009). This alternative neurodiverse representation of autism is further reflected in the terminology used to refer to people without autism —'neurotypicals' or 'NTs' and often the use of 'AS' for people with autism.

Tensions between advocacy and self-advocacy movements have been evident from the development of these organisations. Ward and Meyer (1999) reflect on the formation of AUTOCOM by a parent of an individual with autism in 1990. This organisation was led by parents on behalf of their children, including children who were now adults. The organisation was seen by some to be reluctant to engage individuals with autism on an equal footing to NTs. This led to the development of Autism Network International, to which NT parents were allowed to join, but have no role in the management of it. The development of such self-advocacy movements was greatly influenced by technological developments, which enabled the formation of online self-advocacy organisations (Ward & Meyer, 1999). These offer the potential to link together autistic individuals on a global scale, and provide the opportunity to access a range of materials through which to pursue self-advocacy and to explore different understandings and experiences of autism. It is worth noting that autistic self-advocacy groups have members with a range of neurological functioning and are not purely verbal 'high functioning' people with autism.

In this paper we seek to explore tensions between advocates and self-advocates in a Swedish context with a special focus on how different meanings of autism are produced. Whilst we will draw on Sweden as the focus of our paper we aim to develop arguments more generally about advocacy and self-advocacy, particularly tensions arising from parent run advocacy groups and self-advocacy groups run by adults with autism in this instance. The parents in such groups often have grown-up children for whom they advocate which may lead to power struggles between the groups for right of interpretation and legitimacy of speaking for the group.

Our decision to focus on Sweden has several influences. First, the notion of Asperger's syndrome was introduced early in Sweden by the Swedish researcher and psychiatrist Christopher Gillberg (Gillberg et al 1985). Gillberg and Gillberg (1989), as previously discussed, were the first to publish the diagnostic criteria for Asperger's Syndrome (AS), which enabled new possibilities for individuals to understand themselves from a diagnostic and clinical framework. Christopher Gillberg was also influential in that he worked with the Swedish self-advocacy activist and writer Gunilla Gerland at a time when alliances between NT professionals and autistic people were rare (Ward & Meyer, 1999). Second, Swedish government funding produces a very particular context within which tensions between social movements that are dependent on State funding and those

that are independent of the welfare state are acutely evident. This can be read as part of the role of the groups to be integrated within society (and therefore funded by the State) and those who wish to be separate from mainstream (in this case NT) society and hence independently funded. These issues, which are specific to the Swedish context, mean that Sweden may present a particularly interesting context within which to explore broader issues relating to the tensions within a mixed movement, formerly a more separatist advocacy movement.

Methodologies

This paper draws on a close reading of texts produced by adults within a part of the Swedish autistic self-advocacy movement—a part which is situated within a formerly parent-dominated separatist advocacy movement—for the magazine *Empowerment*. 'Project Empowerment' began in 2001 within the Swedish National Society of Autism (Riksförbundet Autism, RFA). The project aimed to strengthen the influence within the organisation of people with a diagnosis of autism, by for example getting more people with diagnoses on the board of directors at both the local and national levels. However, the RFA has traditionally been dominated (and is still dominated) by the parents of children with autism. The scope of Project Empowerment was diverse, and among other aims it offered possibilities for adults with autism to meet and share experiences and thoughts with each other in spaces adapted to people with autism. An example was Project Empowerment's summer camps that began in 2002. The first camp was attended by over 70 people and was unique in that all participants and most organisers defined themselves as autistic or Asperger's. The purpose of the camp was to have fun, enjoy each other's experiences and to begin a national network of interested people who wanted to engage in the society¹. Around the same time the first issue of the magazine *Empowerment* was published as part of the project. Thirty issues were published between 2002 and 2009, each of these was included in the analysis. For the analysis, all articles in the magazines were read and re-read to divide them into smaller or longer extracts, thematised and put together with all other extracts in the data set focusing on the same subject. Put together, these extracts constituted the same empirical theme. Influence and activism within the movement was one of the empirical themes, and this is the theme reported on for this paper. All 238 extracts categorised as part of this theme were included in our analysis, of these 13 extracts were selected for detailed consideration. The selection was to ensure that data analysis could offer a detailed picture of what it is possible to imagine, talk and say within this specific context about influence and activism within the movement.

The analysis of the articles is inspired by critical psychological discourse analysis (Billig, 1987/1993; Edley, 2001; Edley & Wetherell, 1999; Wetherell & Potter, 1988). We regard the writings in the magazine *Empowerment* as part of an important autistic 'epistemological community' (Whelan, 2007), producing counter-hegemonic discourses that challenge parental and medical dominated meanings of autism. Whelan (2007) argues that people with a diagnosis' interaction with one another constitutes an epistemological community;

¹Hanna Danmo, *Empowerment*, 2008:2, vol 7, p.4–5, "Sex år med tidningen *Empowerment*"

...as well as social, informational, or political ones. They not only share knowledge, but collaboratively formulate and defend an understanding of what counts as 'good knowledge' in order to challenge medical authority and develop patient-centred knowledge claims. (...) Experience, conceived as a social form of knowledge defined, validated, and deployed by a collective, becomes a kind of epistemological qualification—an experiential credential. For groups whose epistemology is experience-based, this form of knowledge becomes the basis for challenging medical experts: without the requisite experience, doctors lack the appropriate epistemological credentials.' (Whelan, 2007: 959)

Findings

Mapping positions in the data. A key focus in *Empowerment* was on the importance of increased participation and influence by people with autism within the Swedish National Society of Autism (RFA). The hegemonic narrative of the organisation is that of integration between NTs and AS; therefore, the joint aim is to work together to produce social change for people with autism. This is expressed through discussions about the work of Project Empowerment and through encouraging readers to become involved with the work. The focus on activities to inspire others to become more active is evident through published reports about activities being done as well as interviews with people with autism who, in different ways have faced a challenge that they managed successfully or who are engaged in inspiring work. Readers are more directly encouraged to take an active part in the work within the organisation. A key issue for this integrationist hegemonic position is that it is important for people with autism/AS to 'come out' and to be proud of who they are within a mixed (NT/AS, i.e. neurologically typical and autistic) organisation.

In the analysis that follows we will document this dominant narrative of a (neuro) integrated autistic politics in which action is to increase influence and participation within the RFA and society as a whole through gradual reforming the organisation and society. We will refer to the hegemonic narrative as a *storyline of an integrationist autistic politics*. In our analysis we contrast this narrative with a more ambivalent counter-hegemonic narrative, which stresses the need and importance of (neuro) separatist, radical autistic politics. From this position working in cooperation with the NTs (mostly NT parents) is, first, negatively compared with working with others with autism and separatist politics. Secondly, the meaning of being involved and taking a more active part within the organisation or becoming members at all in the organisation is questioned. We will refer to the counter-hegemonic narrative as a *storyline of a separatist autistic politics*. We interpret the storylines as expressions of ambivalent discourses of autistic politics.

In our analysis we demonstrate that the tensions between the integrationist storyline which produces a subject position of the 'person with autism/AS' (or 'adults with the disability'), and the separatist storyline which produces a subject position as an 'Asperger' or 'Aspie'. We do this through mapping three key tensions within the advocacy movement operating in Sweden. These are tensions between separatist versus integrated autistic politics and spaces; tensions in the representations of autism as an identity versus a disability; and tensions concerning identity versus interest politics. Each of these key themes will be explored in more detail in the following sections.

Separatist versus integrated autistic politics and spaces

'The struggle shouldn't be for integration, but for power. Once we have power, we can integrate whenever we want.' (Carol Gill)²

'I hope that "we", together, may be about to see how adults with personal experience of the disability are gaining real influence both within the association and the society,' (NT supervisor at Empowerment project)³

The extracts above illustrate a key tension in the Empowerment project, the need to be separate and gain power in contrast to a need to work together to affect change. In the majority of the articles in the magazine the need for both strategies is emphasised, although separatism is mostly represented as a temporary strategy towards the goal of integration, rather than a goal in itself.

In the presentation of Project Empowerment it is stressed that it is a project within RFA (The Swedish National Society for Autism which is the overall organisation that supports the project). The project leadership exemplifies a position of integration, being shared by two people, one described as having an autism diagnosis and the other described as being NT, as well as a steering group which was said to be mainly adults who themselves have been diagnosed with autism or AS.

In the magazine the need for cooperation between people with autism and NTs is stressed in many articles. For example, where the conferences and camps were described it was emphasised that participants:

...we're adults with a diagnosis within the autism spectrum who are members of the Society for Autism. A couple of the participants brought with them one or more (NT) assistants/companions. It was important that the conference would not only be for the most high-functioning.⁴

The camp organisation is also described as something that for the most part were composed of people from different parts of the country, who themselves have autism/AS.

An AS/autistic separatist identity was expressed within RFA and through *Empowerment*, for example in demands for parents to not be included in the activities of the RFA. Articles from this perspective stressed the importance of having a formal diagnosis, and preferably being open about it, as well as enjoying being with (or among) other (similar minded) people with autism. The importance of openness and 'coming out' as a person with AS is stressed in different ways through the magazine. For example readers are encouraged to wear an 'autism-pin' or a special Project Empowerment T-shirt with Project Empowerment's logo on it. In an article about influence and participation within RFA Hanna Danmo writes:

Show that you exist, wear the Empowerment-t-shirt in town! Take your seat, ask questions and make demands! We will not be satisfied with little and not settle for second best!⁵

There are reservations expressed about integration and cooperation with NTs, often in the letters to the editor section of the magazine or cited as secondary sources in articles

²*Empowerment*, 2003:2, vol 2, p. 17, "Anslagstavlan"

³*Empowerment*, 2006:3, vol 5, p. 17, "Anslagstavla"

⁴Hanna Danmo, *Empowerment*, 2004:2, vol 3, p. 4-5, "Lyckad konferens om stress"

⁵Hanna Danmo, *Empowerment*, 2003:3, vol 2, p. 12-13, "Inflytande och delaktighet i FA"

where it is expressed as contributions from ‘other people with autism’ rather than named sources. One example of this is the citation by researcher and autism advocate Carol Gill, which unlike the convention in the magazine is written in English, and published in the letters to the editor section of the magazine. Another example is in a report that criticises the existence of ‘non-disabled people’ in the camps expressed by an undisclosed source in the following extract.

A woman with high functioning autism says: ‘It was good that there were NT people at the camp, it would never have worked otherwise... I would probably never have gone if I did not know that there were NT people there. We are many with food allergies, anxiety, or illnesses that need a lot of support. Even if you have the same disability does not mean you understand each other exactly.’ Sometimes it’s an advantage to have personal experience of the disability to be able to support others. But in other contexts it might be good to not to have the disability yourself, while you may be better to see the overall picture and to think yourself into other people’s situations.⁶

Many of the tensions surrounding separatist and integrated autistic politics reflect the positioning of both parents and their autistic children. NT parents may often assume that they need to ‘help’ people with autism, and such help typically takes the form of enabling their child to be integrated into an NT world.

Autism as an identity versus disability

See Asperger’s syndrome as a different personality and not a disability (anonymous writer in the letter to editor section)⁷

In *Empowerment* there are references to ‘people with autism/AS’ and sometimes to ‘people with the disability’. The use of People-First-language as well as the use of the Swedish counterparts to the English word disability (in Swedish: ‘funktionshinder’) is stressed as important in the magazine in different ways. The magazine consistently used ‘people first’ language whereas some contributors use ‘autistic people’ or ‘Aspies’. The use of the different terms is a further expression of the tension between separatism and integration, with people first language being in line with the integrationist storyline. This is in contrast to ‘Aspies’ who feel that they are autistic people rather than autism being an ‘add-on’ to an essentialised self. The extracts below develop this theme. The differing labels position people with autism in a number of different ways, constructing autism/AS as a disability or as an identity. This is evident in the letters to editor section of the magazine, in which readers and representatives of RFA highlight differing constructions of autism.

(The reader:) RFA believe that the term ‘Asperger’ would mean that one is one’s diagnosis and thus something negative. But the reasoning limps. ‘Asperger’ is a personal name formed of ‘person with AS’—like Stockholmare—person from Stockholm [the Capital of Sweden, authors’ notes]—and no diagnostic name. Hence, I see no reason that the one would be more negative than the other. A further problem with this approach is that language is unnecessarily stilted and even ridiculous: ‘Person with autism/AS’ instead of ‘Autist/Asperger’, a ‘person who lacks vision/hearing’ rather than ‘blind/deaf’, ‘person with movement disabilities’ instead of ‘movement disabled’, etc. To say ‘Autist/Asperger’ is for me a way to defuse the diagnoses and respect

⁶Hanna Danmo, *Empowerment*, 2004:3, vol 3, p. 4-5, “Projektets sista läger”

⁷*Empowerment*, 2002:1, vol 1, p. 16-17, “Insändarsidor”

the person behind.... Personally I think it is 'person with autism' which is the negative formulation. It is a position, a nasty labeling. Diagnostic criteria are often located close to the personality. So why not accept people as they are, as Autist/Asperger and that it is a part (but not all) of the personality? Now it is a fact that many Asperger themselves prefer to call themselves just Aspergers, or sometimes 'Aspie'. Why can't RFA respect that??? [Name of reader], Asperger

Answer:

...within the National Society of Autism, we have long held the view that one *is* not one's impairment but you *have* an impairment. Primarily, we believe that every person is a unique individual with individual talents, strengths and impairments. That view is reflected in the choice of which expression we use in our magazines. In the future as well, we will use 'person with autism/AS' in the magazine *Empowerment*. What people choose to call themselves, however, is another matter...

Eva Nordin-Olson

President of RFA⁸

The tensions between two alternative terms of reference are made clear in the exchange above. The reader who initiates the discussion draws on a separatist storyline to argue that autistic people should firmly align themselves and renegotiate the meaning of their own diagnosis through owning the label as part of themselves and their identity. However, the spokeswoman for the RFA remains firm in her position of the use of people first language, drawing on an integrationist storyline, stressing an integrationist 'we' within the movement.

Identity politics versus idea-based/interest politics

During the project period, there has been a debate about which target group that takes the most space in the association's activities. Parents of children with the disability have, to some extent felt neglected since our target audience made the entrance. We hope that this discussion does not lead to divisions within the association, instead that we agree on common points, and that we otherwise can go side by side. The association's activities is about to fight for everyone's rights and against ignorance and prejudice about autism/AS. Seen from this perspective it is for us of course that we continue to fight together.⁹

In the extract above the tensions between adults with autism and parents are discussed. Those are central too in discussions about the purpose of Project Empowerment, the Empowerment Council, and the local support groups of people with autism in (Swedish 'träffgrupper'), as well as the magazine.

The two main goals of the organisation clearly illustrate tension in positioning autism, these are: representation for people with autism on boards and, second, the creation of separate social meeting spaces. The goal of creating possibilities for integration through increasing influence and participation stresses the need for people with autism and NTs to work with each other regardless of whether they identify as autistic or NT. Whereas the goal of separatism was to form separatist forums where people with autism can meet, share

⁸*Empowerment*, 2008:1, vol 7, p. 17, "Insändare"

⁹*Empowerment*, 2004:4, vol 3, p. 13, "Nätverk och inflytande"

experiences and discuss issues of importance to them on their own terms. The importance of cooperation rather than autistic separatism is seen, for example, in the emphasis on working with ‘interest politics’ including socialising and sharing everyday life experiences in the magazine.

With the closure of the Empowerment project the alternative suggestion was that the association must find new ways of working in the form of ‘*interest groups*, where participation is based on interest in targeted areas and not on the member group you belong.’¹⁰ (i.e. whether you identify as autistic or NT). The assumption was that integration was the way forward and that it did not matter whether you have a diagnosis of autism, are NT or describe yourself as a parent of a child with autism.

The discourse of separatism was drawn on to challenge the importance of getting more influence and participation with NTs and to stress the importance of forums to provide opportunities to meet others with similar experiences. The forums, among them the summer camps and the local support groups, which have made it possible for people with autism to meet others in similar situations and to participate in a social context in which they enjoy, is represented as having played a major role for many of the members

The rivalry between the two positions and the power of the integrationist view is perhaps expressed most clearly in discussions of the merger of *Empowerment* into *Ögonblick* in 2010. The argument for the merger was based on the idea of increased influence, that ‘The material from the magazine *Empowerment* will then reach out to all members and subscribers and have a much larger readership. This means greater opportunities for information and influence.’¹¹ In the texts that focus on the merger it is emphasised repeatedly that in this way non-autistic members of RFA will ‘be able to take advantage of what is written of us with autism/AS’¹²—which means according to one statement more opportunities for information and influence within RFA—but also that this means less work for the supervisors at the office. In the readers’ responses to the merger the value of cooperation is emphasised, alongside the value of integration. In contrast the magazine was also used to emphasise separatism and the meaning of an autistic forum for adults with autism, as something that in itself has meant a sense community for adults with autism, as a companion, an opportunity for people with autism to identify with other adults and therefore not to feel alone. The upcoming merger resulted in anxiety among some readers. One reader wrote in the magazine:

I am now a little worried about what happens when [the magazine] *Empowerment* is lost. (...) I hope that we will not be in the background. Also hope that the merger of the papers will be good. I have had advantages of *Ögonblick* but felt that the magazine *Empowerment* has been better. *Ögonblick* was more about children and youth, and took up more autism. The magazine *Empowerment*, it was more about Asperger’s syndrome, and about people of all ages from 18 years and up to the elderly. I hope that adults with Asperger syndrome will not be in the background of the new magazine, but that it will be written as much about us.¹³

The tensions between identity politics and ideas-based/interest politics are therefore

¹⁰*Empowerment*, 2009:3, vol 8, p. 2, “Projekt Empowerment”. Se även *Empowerment*, 2009:3, vol 8, p. 14, “Rådet har fullgjort sin uppgift”

¹¹*Empowerment*, 2009:3, vol 8, p. 2, “Projekt Empowerment”

¹²See for example *Empowerment*, 2009:3, vol 8, p. 16, “Aktuellt”

¹³Kerstin Blomkvist, *Empowerment*, 2009:4, vol 8, p. 6, “Tidningen betydde mycket för mig”

clear in the expressions within the magazine *Empowerment* and ultimately in the actions of the RFA in closing the Empowerment Project. Such expressions also draw on the tensions between separatist and integrated autistic politics, and a concern is again raised with respect to the domination of NT voices at the expense of the potential marginalisation of autistic voices within the newly shaped structure.

CONCLUSIONS

The analysis reports two competing discourses: an integrationist (or reformist) and a separatist discourse. They are producing two quite different subject positions and by implication different forms of collective action/activity. Through the more integrationist discourse a subject position as a person with autism is produced and through a counter-hegemonic radical discourse a subject position of the 'Aspie' is produced. The integrationist discourse underlines a goal of incorporating people with autism into the social/NT world. Hence action is focused on (political) representation through activities such as increased influence and involvement in the association through board representation and formal representation on boards. It may be understood as an important to position people with autism as *full members*, with a *full membership*—within the advocacy movement. Political representation is an important aspect of membership, and comparisons with citizenship in a nation can be made. In order to be included as full members (citizens) in an organisation, adults with autism need to be regarded as legitimate members in their own right, on their own terms with respect to autistic advocacy, rather than as objects within the wider membership pool (for a discussion on citizenship and learning disabilities see for example Redley & Weinberg, 2007). The integrationist discourse can be viewed as a result of a negotiation, where full membership (in terms of representation on boards, questions concerning or of special interest for adults with autism being included as part of work of the organisation) in the parent-dominated organisation is on the parents' terms and granted on the basis of specific norms and expectations. These include working together i.e. neuro-inclusively with NTs and draws on a definition of autism as a disability (a deficit) a person has rather than an identity (expression of a personality).

In relation to this an alternative construction of the autistic person is produced through invoking the counter-hegemonic separatist discourse. Such a narrative produces the 'Asperger' or 'Aspie'. Here the 'full membership' refers to a sense of identification with, sense of belonging to and being at home with other people with autism, it does not include NTs within this. It is expressed through active involvement in the autistic self-advocacy movement and encouraging autistic only spaces and forums where people with autism can meet and share experiences on their own terms. From this position, it is important to be open about one's diagnosis and part of the autistic self-advocacy movement's production of a 'proud Aspie'. However, tensions can be attributed to the perceived aggressive nature of an identity politics based position, with Ortega (2009) noting that the neurodiversity movement only actually constitutes the minority of people with autism. The diversity of positions within this debate therefore needs to be respected in any considerations of the autistic advocacy and self-advocacy movements.

Reflecting on the role of parents and autistic people within advocacy movements, Broderick and Ne'eman (2008) note that, while groups may share many similar goals in terms of public policy and social change, their positions remain divided. Such a division for

Broderick and Ne'eman reflects the perceived secondary position of the self-advocate narrative within the wider discourse of autism advocacy movements. This division is evident in our analysis of the work of the Empowerment project and its magazine. One key tension between the two discourses reflects the subject positions made available for take up by individuals: separatist discourse providing subject positions with empowering identities, but may be (as in the instance discussed in this paper) limited in the extent to which separatist identity politics can challenge the mainstream position, in the case of our work of NTs and NT dominated society. While this paper has drawn upon autism advocacy and self-advocacy movements as an example to demonstrate the tensions between positionings of individuals through dominant discourses, the key tensions evident in this example are ones that we would expect would be evident in other groups, where competing voices 'speak for' individuals.

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