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## Introduction

Commentators on the “autism wars” (Orsini 2009; Chamak 2008) illustrate the competing meanings of autism and what is required in terms of support for autistic people. Meanings have been produced as different *autistic knowledges* (where knowledge is produced by autistic people, such as formulated within groups of autistic self-advocates, adults and academics) and as *knowledges of autism* (as knowledge produced by non-autistic people, such as formulated within groups of non-autistic parents of autistic children, academics and professionals). These knowledges have competed over rights of interpretation including formulating best practice in support aimed at autistic people. In this chapter we conceptualise these claims to knowledge and rights of interpretation in terms of struggles within and between different epistemological communities for authority with a particular focus on support.

We use the conceptual tools of epistemological community and epistemic authority to think about different languages at play within epistemic communities that serve to define and produce meanings of support for autistic people. The conceptualisation of epistemic communities and epistemic authority helps us think through how meanings of support aimed at autistic people are spoken of in different support contexts and to think through positions in relation to autism, specifically in the move for autistic young people to adulthood. This analytic is useful to examine how some knowledges become shared and powerful across communities whilst others remain within a particular community.

In the following sections we identify the languages at play in the conversations about support aimed at autistic people that we have had with people representing different epistemic communities, situated in different, but in certain ways also similar, contexts. We are using ‘languages’ as a way of referencing context, both linguistic (conversations across English and Swedish) but also across autistic/non-autistic worlds and academic/practice. To illustrate our arguments, we will draw on a series of conversations we have had with each other and with others in Sweden and the UK. The discussions took place in a time when, in the UK and Sweden, counter narratives to the epistemic authority of medicalised and deficit understandings of autism were beginning to be evident in mainstream (non-autistic) discourse. Some were recorded and transcribed, others were informal. Our conversations took place in and from the perspective of different contexts: autism advocacy/activism, researcher, university based, practitioner/NGO, and also across the national contexts of Sweden and the UK. We examine how these conversations draw on different languages of autism and how these position autistic people in need of support. We are using ‘autistic people’ as a way of referring to people who identify with autism and ‘non-autistic’ people for those who do not.

## Epistemic communities and autism

Feminist theorist Lynn Hankinson Nelson (1993) has conceptualized “epistemological communities” as “agents of epistemology”, where “agents or subjects of epistemology”, are “embodied and situated in specific social and historical contexts” (p.121). As such, Nelson suggests that members of these communities contribute to constructing knowledge about their own lives. These communities shares knowledge from other sources of information, evaluate

the value given to these knowledge sources, and community members both “construct and acquire knowledge” (p124). They are therefore both recipients of knowledge about their lives and co-constructors of this same knowledge. However, the process of the evaluation of knowledge requires decision-making by members of these epistemological communities as to what knowledge is credible, and this process can be understood as depending on ‘epistemic authority’. Epistemic authority is defined by Oikkonen (2013, p284) as “the belief that the proposed account is the most accurate one”.

In a condition as highly medicalised as autism, the parameters of which are laid out in medical practitioners’ diagnostic manuals, it follows that the most credible testimony which may be assumed to be the most accurate, and which is most commonly published (Murray, 2018), issues from medical science. Therefore, the sources on which particular communities base its co-construction, the starting point for discussion, is likely to lean heavily on a medical ‘story’, which in turn takes an assumption of deficit as its starting point.

Whilst counter narratives to the medical ‘story’ have flourished within some autistic-led community spaces it is perhaps only recently that those rejecting a purely deficit model of representing autism have received much mainstream attention either in academia or within broader culture. Hence there was not a formalized language to oppose deficit orientated talk. It has been argued those from differing communities of practice may lack understandings of effective ‘cross-neurotype communication’ (Hillary, 2020) or ‘interactional expertise’ in understanding the cultural practices of ‘outsider’ communities (Milton, 2014). This can be particularly problematic in misunderstandings and misrepresentations of autistic community and culture, and concepts such as neurodiversity (Walker, 2014).

#### Contexts of the discussions

Our conversations took place in, and from, different positions on the non-autistic-autistic spectrum and in different languages (Swedish and English). The people we have had conversations with are all practitioners working with supporting young autistic adults to employment at the regular (non-autistic led) employment market. They work within a similar frame of thinking about autistic abilities, drawing on a strength-based model on autism informed by neurodiversity ideology (Walker, 2014).

The first conversations were with non-autistic people working at a non-autistic-led service which includes support for autistic people and people with learning disabilities in the UK. The conversation took place between Hanna (a Swedish researcher with English as second language) and Lindsay (a British researcher) and two non-autistic women working at a charity assisting young people with learning difficulties and/or with autism. The conversation took place in an office space at the charity. One woman took part via telephone.

The second conversations were with autistic people working at an autistic-led support service in Sweden aimed at young autistic adults. Hanna had been a follow-researcher in the Swedish group for two years. The Swedish group was therefore familiar with Hanna and the experience of being participating in a research project as a group (Bertilsdotter Rosqvist, 2019ab). The conversation which took place in Sweden with Hanna and Lindsay and the members of the group can therefore be seen as yet another such follow-researcher meeting, with the difference that the conversation now included a person new to the group (Lindsay) who also did not speak Swedish. The Swedish group consisted of six autistic people; three women and three men. It took place at a conference room by the work space of the group in a middle-sized Swedish town. The conversation took partly place in Swedish and partly in

English. Although all participants understood English, most felt most comfortable expressing their thoughts in their native language, Swedish. The Swedish participants including Hanna translated some parts of the discussion in Swedish to Lindsay during the conversation.

A third conversation we had was together as a group of researchers and took place in a British university space. Our positions vary across identifications in and between autistic and non-autistic positions. Among us, Damian (a British researcher) was involved in a neuro-mixed support service where leadership is shared by non-autistic and autistic people.

All conversations were recorded and transcribed by professional transcribers. The recording in the Swedish context was transcribed by a Swedish transcriber who also translated all transcripts into an English-only text.

#### *National policy as language and claim to epistemic authority*

A key language that produces epistemic authority is a policy, legislative discourse. It conditions ways of working with autistic people, how support oriented towards autistic people is funded and organized.

The UK provision should be seen in relation to the huge cuts to ‘welfare’ payments that have been a consistent feature of the coalition and now Conservative governments. The erosion of the welfare state has meant many services seen as essential to the wellbeing of disabled people have been cut. Support is provided by a mix of state and third sector organisations, mainly charities. Hence the language of policy and legislation in the UK is framed around disability rights generally (including the *Disability Discrimination Act*, 1995; the *Equalities Act*, 2010) and specifically in relation to autism, the *Autism Act* (2009) and *Fulfilling and rewarding lives: the strategy for adults with autism in England* (2010). The Act and strategy have required local authorities to appoint leads for mapping the needs of autistic people and their families/carers, and plans for engaging autistic people in planning and designing services. The policy also refers to the *Children and Families Act* 2014 which sets the expectations for support for autistic children, including the transition to adult services. The update to the Strategy in 2014, *Think Autism* describes autistic people in terms of rights, “people with autism have an equal right to a fulfilling life, just like anyone else”, seeing the responsibility for fulfilling these rights as something that is shared across services and government, “It is time for us all to think autism”. The discourse also views ‘people with autism’ (in contrast to ‘autistic people’ which is a term more commonly preferred within the autistic community) as individuals (as seen particularly in the notion of personalization), with possibilities to with right kind of support “make the most of their talents” (Think Autism, 2014).

In Sweden support is mainly funded and organized by the welfare state. The Swedish disability reform from 1994 includes the Act Support and Service for Persons with Certain Functional Impairments (LSS). LSS focusses on cooperation between the various authorities to help people with disabilities to participate in society. In LSS, ten forms of assistance are included. Among them are rights to support to daily activities. Daily activities can be carried out within a sheltered employment, such as a day centre, or at the regular employment market with certain support to disabled employees and employers (subsidized wages, certain financial support to work place adjustments for the disabled employee). The Act divides different disabled people into three “person circle”-groups where each group are entitled more or less support. Autistic people have been included within the first group also including people with learning disabilities, while people with ADHD were added later to the third group also

including people with psychiatric disabilities. Most programmes for people with learning disabilities focus on placing people in specific programmes with activities to support their training. For people with psychiatric disabilities, the primary aim is to support the coordination of formal services in order to rehabilitate the person in the community, with the goal of eventually participating in the regular employment market. A solution regarding autistic people with no learning disabilities or people with ADHD with more support needs is a mix between support directed to either people with learning or psychiatric disabilities. (Winberg et al, 2019)

### Language of policy and ‘reasonable adjustments’ or tailored support

In British policy the notion of ‘reasonableness’ is important in determining the extent to which ‘mainstream’ cultural spaces (Milner and Kelly 2009) need to be accessible to disabled people. The assumption is that spaces, in particular workplaces, dominated by non-autistic people need to be reasonable and proportionate in their adaptation for the (non-autistic) environment and working practices. We reflected on this when we spoke together:

Damian: Just being one of the things that we talked about [...] is around work. I think a lot of the stuff that’s happened around work has been very tokenistic. It’s kind of the concept of reasonable adjustment that I’ve written about and talked about before, because it’s kind of reasonable to whom adjusting from what. So reasonable to the person in power adjusting normality to make a special exception for you and your special needs it becomes, and it’s very rarely done in practice or acted upon. And one of those words that you hear is compromise, like you just need to compromise more Damian. It’s always the autistic people in my mind who are bending over backwards to compromise and change against our better nature sometimes, while you see absolutely none sometimes coming the other way. It’s that assumption of normalcy, this is just the way things are done, so get used to it and that’s kind of assumed ableism in a way which is so ingrained it’s kind of hard to understand at times.

The concept of reasonable adjustment can be contrasted with that of Universal Design (Milton et al., 2016) which rather than making bespoke adjustments that separate out those deserving or not, would seek to ensure environments and products are useable by the widest range of people possible.

Within non-autistic-led support service, the language of individuality- the autistic person as a person “with autism” is brought into conversation in which support is framed through a language of personalization and individualization. The assumption is that individually adapted or tailored support is an important consideration in service provision. The importance of individually formed solutions is argued through discussions of a different ways of offering support depending on individual’s needs.

Central in this is meanings of strengths and abilities, and the possibility for non-autistic coaches to access abilities or support people to develop and maintain their abilities. This idea of “ability” is formulated in talk of the UK practitioners as an individualized capability (“very much around kind of the people themselves” British charity worker, R1). R1 further says:

And it's quite a kind of detailed in literal assessment and vocational profile around people, kind of really getting to know the level of experiences they've been before, what's worked for them, what hasn't worked for them, what do they want to do, looking at the kind of gaps, and then working with them to match them to jobs really. And working with employers the other way as well, but really looking at what they want from an employee and what is the job. You know, we've even done kind of things where we've done shifts with people just to kind of find out a bit more information about the job.

Lindsay: OK, so you've gone along and kind of shadowed someone doing a particular job.

R1: Yes. So, we've got a really good idea of what the kind of duties of the job, what the dynamics of the job. I think particular with people with autism, the issues we found before was that it might not be the tasks of the job; it's the whole culture of a workplace that can have an impact of it being successful for somebody.

As part of this individualized approach to support for autistic people are references to a concern that the autistic people the non-autistic support service worked with did "not want [...] to be different" (R1) and hence services were built around bringing them into mainstream (non-autistic dominated) systems. The idea of "not wanting to be different" sits uncomfortably in relation to meanings of rights of "reasonable adjustment" which is based on accepting one's difference (i.e. support needs). For example, Hanna asked the two British practitioners about their understanding of how 'reasonable adjustments' enable their work and position autistic people:

Hanna: Do the participants in your, so the people you are kind of coaching, are they getting this idea of reasonable adjustment, as to what they understand about their rights and what is possible for them to kind of get?

R1: I think people's understanding depends on the person themselves. I think people are very scared because I think they think it will make them different. And I think it's about looking at doing it in a kind of not such legal terms, it's what will make you do your job well, rather than ...[unclear] in that we need the employer to make a reasonable adjustment, that kind of thing. And I think people themselves, it has to be much more practical for them. So it's really going in-depth with these are the tasks of the job, what do you think, you know, what would you find of support in this, what can we do within these are the structures to help do it better. I think people really struggle with the concept that they're asking the employer for reasonable adjustments and they don't want to be different.

One way of conceptualising the work undertaken as part of the non-autistic practitioner's role is that of a cultural or language broker. This concept was originally developed to understand the work of children (and adults) translating for family members who do not speak the majority language of the place of residence. The activity is not purely a linguistic act of translation but a cultural brokering or mediating between different cultures (Abreu & O'Dell, 2017). A similar concept of mediator or broker was discussed by Brownlow (2007) in her work examining 'autistic cousins'. ACs, people who are not autistic but have awareness and knowledge of autism and work to mediate between autistic and non-autistic worlds and translator of mainstream cultural spaces of work. It also echoes the work of Goffman (1963, cited in Ryan & Runswick-Cole, 2009) who draws on the concept of 'the wise' who, in this

context, have an awareness of disability because of knowledge of a disabled family member. A central aspect of this is the task of the non-autistic professionals to talk with their clients about a future in which they can see themselves as “citizen-workers of the future” (Lister, 2003). The support is to translate expectations for the autistic person and enable them to better fit in, ‘integrate’ with the work culture.

R1: So we had a number of incidents where for example somebody said you can take a break anytime you want, and that person ended up taking a break all the time. And we have to lay down some kind of rules that certain rules that people don’t always read, like is it a ‘dress-down Friday’ place. And we kind of need to get to know some of those things so people integrate much more. You bring a cake on your birthday, those kind of things, because I think sometimes the workplace culture can have quite an impact, and it’s also where you see how you communicate. For example, we’ve got somebody’s who’s an apprentice with autism at the moment, and one of the issues that we’ve had is he has got quite distracted, because of where he’s been sitting, and he’s been talking to lots of other people rather than getting on with his work. So we’ve had to kind of do some work about how the office runs. And kind of change his desk so he’s got kind of separate space and can concentrate.

R1 stresses an important part of her job as coach to understand workplace culture and how the person learns to work. She also stresses the coach as a messenger and mediator between the autistic person and the employer. This positions the non-autistic support person as someone with epistemic authority to lead cross-neurotype communication (Hillary, 2020), to *cross-neurotype translate* non-autistic work cultures. In this case cross-neurotype translation include to define what is reasonable adjustment and the task of the autistic employee (to adapt to work spaces dominated by non-autistic people). She says:

“also it’s people themselves. You know, people are the best advocates of what works for them. And we’ve got people that will write down what they want us to tell an employer before they go in. One guy said that he won’t interact at a team meeting because he doesn’t like talking at team meetings, but he will email after the team meeting his suggestions. And that’s what he wanted us to tell the employer: he will go but he won’t interact in those team meetings.

Lindsay: And then employer’s OK with that, I’m assuming, to...

R1: Yes, it’s a reasonable adjustment. And because we’ve done quite a lot of work around disability awareness and working with the kind of staff team around that particular individual, they’re fine with it. Because it’s not something that we’re saying that they can’t do the job, it’s just an adjustment.

Hanna: What is a reasonable adjustment?

R1: Basically, it’s having a reasonable adjustment in terms of, normally at the team meetings people are expected to all contribute. At this team meeting he’s not but he will contribute in a different way.

The position of the support worker as cultural broker ambivalently sits in relation to the demands of epistemic authority of the (assumed to be) non-autistic employer. In the narratives of the practitioners we spoke with, employers are positioned as possibly inflexible when it comes to recruitment methods. The practitioners stressed that the job of the non-autistic coaches is to make the employers “a bit flexible” and suggest alternative recruitment methods. Their view was that employers find the approach difficult:

R1: (...) And particularly the public bodies find that very hard to kind of shift things about and why are we doing it differently for one. I think the other thing is that, you know, physical space in offices to have a job coach in can be very difficult. And we have to make some compromises there. I would also say that it's about setting as well, because you might get a couple of good people but it's making sure the whole of the team is aware of somebody's needs. And what we have found is that it's very useful to identify a kind of workplace buddy for somebody. That they've got one person that they answer to and that they can go to if they've got any issues at work. Because if you've got lots of people telling you what to do it can be very difficult, you know, it's very difficult for anybody that.

The coaches draw on their epistemic authority as knowledgeable about autism and autistic people to show how the employers can learn from the coaches to see the ability of the disabled employees; "I think the other thing is that once people can get over the barrier, if you can see how skilled people are, I think people are worried that people aren't skilled because of their disability."

In these conversations employers are represented as people in need of a bit of coaxing into becoming supportive to autistic employees. The charity's employment service worked with employers to get people into employment. In conversation it was clear that the practitioners we spoke to assumed that employers were concerned about the additional work load of bureaucratic process, and a sense of not knowing "if we can put the time, will we manage it, etc. etc.". The role of the coaches was described as a broker between autistic clients and non-autistic employers, as someone who works with employers and workplaces, which later on become more confident and knowledgeable and are able to include more disabled employees. For example:

R1: So again, I mean we, [R2] and her team have been working with, it's a school catering business and our apprenticeships here are mainly in catering, so we're trying to always find placements and people to move in. So we've worked with the firm about two years now? [name of employer]? Yeah. And they've given four jobs, out of, probably about eight or nine placements that they've had, of people so pretty good. And again he came to speak at this event we had last week and he was saying, you know, it's definitely had its challenges. We've learned what to do and we've learned what does work what doesn't work. But this year now he feels confident enough to offer I think it's about 19 placements. So it's about a trebling of placements that he's willing to offer across all his different businesses and hopefully out of that maybe again, you know, 50% or more will get work out of it, because some people doing the placements won't want to do that sort of job themselves. It's a chance to see it and other people maybe will need a bit more before they will be successful in getting jobs. But it's a very good step. And that sort of partnership, because he feels confident in [...] team as well, that people are there to support, if anything does prove challenging for them as an employer, that seems very important to that company. It's not a big company but they've got quite a lot of jobs. But it's not a national company or anything like that. And I think they feel confident now to take that forward.



## Language of autistic support to autistic people

Central in the formulation of an epistemic community is the real or imagined community space where shared language and concepts, collective ‘public conceptual schemes’ (Nelson, 1993) which structure and make intelligible narratives of experience and legitimate particular sets of theories, concepts and standards, can be taken for granted. Our discussions with the Swedish group exemplified the notion of shared autistic spaces (Sinclair, 2010), seen by the Swedish group as psychosocial space, opposing the “lone autistic self” (Bertilsson Rosqvist et al, 2020b) as present in the individual approach of the non-autistic coaches. This includes a sense of belonging to that space. For example the group refers to experiences among autistic participants in those spaces, even those coming there for the first time, to “feel like they are ‘home’ and they can be themselves” (F1). This is also reflected in the UK context, where autistic-led spaces are seen as often less judgemental and understanding of autistic needs and beneficial to wellbeing (Milton and Sims, 2016). Central in the narratives of this space in the Swedish conversations were particular ways of socializing and communicating. For example the group refers to a great need among autistic people to discuss with other autistic people things of genuine interest, around a particular topic (c.f. Bertilsson Rosqvist, 2019a) perhaps reflective of an ‘interest model’ of autistic sociality (Murray, 2018; Bertilsson Rosqvist, 2019a). For example F1 says:

F1: (...) And that we have fact, that we have knowledge, and that we talk within ourselves, from within ourselves. That is very, very essential. And we were thinking of that, that... what might be different is that we have very genuine interest when we communicate... when autistic people communicate, often we communicate with our whole body. And other autistic people understand that the best, because you are very... yeah. We think that is very, very, very important. (...) it’s like... It’s a great focus on... the topic. [...] We are very much “here”.

In relation to this way of socializing and communicating, the group discussed cultural communication more dominating in non-autistic groups, which is defined as “doing all sorts of communication in the same time and that makes it a bit messy.” (F2). In the narratives about the autistic space, the common interest and intense focus on what is being discussed is stressed. Understandings of autism within the autistic space, is contrasted to understandings of autism within the public realm or non-autistic understandings of autism. In particular, understandings of autism as something puzzling or associated with learning disabilities, pointing at lack of effective cross-neurotype communication (Hillary, 2020) is stressed by the group.

F1: I think it's very hard for them to ... eh. I think the vast majority do not know at all what autism is or how to understand it at all. But what you see is that you see that there are some people who are a little stiff, speak a bit rigidly, so this is the sort of thing that is, too. That there are people who in some way distinguish themselves from, a bit. And that it's a group you do not really understand. I think so.... I unfortunately think so. In relation to what [non-autistic] people have seen, they judge an autistic person the first time they met.

F4: Yeah, if you tell someone “I have autism”: “No, no, you can’t have that. I didn’t think... I don’t think so.”

F1: “You look so normal.”

F4: Yeah. “You look so normal.”

[...]

F4: They think autistic people don’t like to be hugged, doesn’t want you to touch their ears, or... Like to have strange clothes, and... stuff like that. Like trains. [laughs]

The Swedish group viewed the expectation to ‘fit in’ in workplaces (evident in discussions with the British practitioners we spoke with) as associated with non-autistic cultural norms of sociality. For example F4 says:

F4: [unclear] ... you should not stand out. You must not be different, you should well ... dress like the others, you should be just like ... like the others, and laugh at the same things. One laughed at the different ones, as well, and then it was often that you were laughed at. Rather than being included and laugh. And then you thought, uhm, at school, you were mean to each other, and you do not want to be mean, like. And then you were anyway ... You spoke up because others were bad, then became the victim oneself.

The importance of fitting in socially, is associated in the group with definitions of social competence in social circles dominated by non-autistic people, which can be thought of as non-autistic epistemic authority when it comes to meanings of communication and sociality.

#### Questioning non-autistic epistemic authority in support to autistic people

A way in which non-autistic epistemic authority has been challenged by autistic people is through the construction of autistic epistemic communities which break the isolation of autistic people, forming a counter-hegemonic voice in relation to more dominating non-autistic voices. It also suggests the development of autistic communities rather than isolated autistic individuals. For example in experiences of young autistic people, going through university having never knowingly met another autistic person. Damian recalls:

I went to an alumni group that disability support workers at a university set up, and then there was about 20 autistic young adults in the room who had all gone through their degrees, and one of them early on said why didn't anyone think it was a good idea to do this when we were at the university rather than finished. And a couple of people who've got through university never knowingly met another autistic person and they were in this room sharing stories, empathising with each other within ten minutes or so, [...]. They just took over. And I think what is important sometimes is that awareness of others and strength in numbers. Kind of, if the amount of meetings and forums and working groups I've been on where I'm the only autistic person in the room or one of two or three, we're always in the minority. And when you're in the majority it's like the straight guy at the gay club, it's kind of suddenly the power shifts and that's quite a powerful thing to not be a minority all the time.

The impact of not being a minority, being a majority, illustrated both in the recalling of the Swedish group and in Damian's extract above, illustrate a current move within both support and research, where non-autistic led research/support is being challenged by autistic led support or research. During our conversations together we explored histories of autistic-led support and non-autistic led support albeit in close cooperation with autistic people. Both stressing the active involvement or participation of autistic people in designing and implementation of support oriented to autistic people.

In the discussions between the three of us as authors, we picked up on the idea of the different meanings/language of (autistic) collectivity versus (autistic) separateness (the individual approach or the lone autistic self) (c.f. Bertilsdotter Rosqvist et al, 2020b) associated with different knowledges about support aimed at autistic people, among the people we have talked

with. The becoming aware of each other as an autistic collective to challenge the separateness and isolation of autistic people from each other are repeatedly stressed by autistic people while the individuality of an autistic person is stressed by non-autistic people.

A dilemma was brought to surface, when discussing the degrees of involvement or epistemic authority of autistic people. In our discussions Damien made a distinction between autistic-led research, which refers to something which “tends to be more critical, more sociological, more practical” and “non-autistic research”. Our discussion addressed imbalances within critical research on autism, Damien invoked the terms “ontological ownership” of autism. By illustrating with the “Glass Subheading” (Milton and Bracher, 2013, Milton, 2014) non-autistic ontological ownership is mapped out and the risk of tokenism/being bracketed in the corner by non-autistic people within critical research on autism which is not autistic-led but rather as non-autistic led with participation of autistic people:

“the Glass Subheading in articles and in research where the autistic person was quoted and misframed often, but is rarely the person writing the conclusion or doing the final interpretation of what this all means. So, the ontological ownership of autism is rarely in the hands of the autistic person, whether it’s TV or research or anything else. And the autistic led stuff tends to be very much unfunded people’s voluntary goodwill and kind of that grassroots activism type stuff.

## Concluding remarks: meanings of collectivity versus separateness in support aimed at autistic people

In this chapter we have used a series of discussions to illustrate the different meaning making languages of autism and how they position autistic people and support services. Non-autistic support people stressed the importance of providing individually-tailed support services where autistic individuals (rather than autistic collectives) are coached in skills to manage a non-autistic work culture. In the autistic discussions the focus was on the sense of being part of a community (a collective) where people meet because they want to do things together rather than to be taught stuff by non-autistic people (in order to be able to integrate more smoothly within worlds dominated by non-autistic people). In terms of epistemic communities, the autistic narratives stress the importance of forming autistic epistemic communities where autistic knowledge is shared and produced within that community, through “shared language and concepts”, rather than what can be looked upon as non-autistic epistemic authority in settings dominated by non-autistic people. This can be in settings led by non-autistic people, or a non-autistic talking across non-shared languages (non-autistic versus autistic) and non-autistic-autistic mixed settings where non-autistic ways of being (in this instance in the workplace) are assumed and naturalised. We have conceptualized this in terms of different languages, how languages can be spoken across cultures and frame understandings of support. The language of deficit, personalization and individualization can be seen to maintain non-autistic epistemic authority through the isolation/separateness of autistic people from each other (as discussed by Damian in the case of support systems).

The inclusion of autistic researchers and the lived experience of autistic people are becoming more evident in mainstream non-autistic knowledge production and service provision. For example, in a seminar series ‘Shaping Autism Research UK’ participation (alongside autism practice and policy) were key themes from the outset, this became even stronger through the course of the project (Fletcher-Watson et al., 2018). Alongside these efforts was the establishment of the Participatory Autism Research Collective (PARC), an autistic-led

network championing participatory research in the field (Milton et al., 2019). Despite these efforts, autism research is still dominated by medicalised deficit model approaches. These competing knowledges also have their impact on practice, although possibly creating a contradictory and confusing space for practitioners working with autistic people to navigate.

Whilst conflicts over epistemic authority continue these tensions are worsened by a lack of understanding between perspectives (Milton, 2012; 2014, Hillary, 2020) and what has been described as ‘silo mentalities’ (Cilliers and Greyvenstein 2012; Arnold 2016) within academia (in relation to barriers to interdisciplinary work). Such a ‘double empathy problem’ is situated within wider power dynamics (Milton, 2016). Whilst safe autistic-led spaces that can be trusted are growing, they may have limited impact on the epistemic authority of non-autistic people to define the lives of autistic people across many contexts in which they live. A strength and a weakness perhaps of autistic community efforts are their often fragmented and disparate character.

Through this chapter we have aimed to contribute to a current debate of epistemological authority in meanings of support aimed at autistic people. With this, we also pose some theoretical questions for further consideration: how is epistemic authority (or ontological ownership) of autism invoked and defended in different contexts? What “autisms” and “non-autisms” are produced through different contextual epistemic authority or power bases of autistic knowledge production/production of knowledge about autism? How is autistic knowledge/knowledge about autism produced in different autistic or non-autistic spaces? What do non-autist-defined/led and autistic defined/led services for autistic people constitute- and how could they work together.

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