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Knowing what to do: exploring meanings of development and peer support aimed at people with autism

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ABSTRACT
Non-autistic people is frequently described as best positioned to provide support to autistic people. But what could autistic peer support, where the support actor is another person with autism, mean? The aim of this paper is to explore different meanings of development and peer support at an autistic-only work place in Sweden. The analyses in this paper is based on data from a field work among a group of autistic self-advocates in Sweden. The group is working together in a three-year autist led project aiming at supporting young adults with autism with life strategies and with peer-to-peer mentoring as well as educating employers about autistic abilities. In the group ideas of an alternative autistic development to be nurtured and supported by autistic peer support is brought forward. Support to autistic people has to be based on understandings on autistic functionality and ways of developing and learning. This includes support in executive function, formulating goals and future aspirations, support in to get to know your abilities, embrace and cherish your strengths and interests, and get to know your difficulties including strategies to manage them, without reinforcing a sense of failure.

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Autism; peer support; autistic peer support; empowerment; Sweden; self-advocacy

Introduction
Peer support aimed at people with autism is often based on ideas of age-appropriate developmental tasks. Autism is commonly represented as a failure in succeeding in important developmental tasks such as social development and independent behaviour. As a pervasive developmental disorder, it is characterised by underdeveloped social and communication skills (Higgins et al., 2008).

Leaf et al. (2011) note that some interventions focused on improving functional skills and intellectual scores as well as minimising problem behaviours among children with autism have led children with autism to become ‘indistinguishable from their peers’. Some people with autism rather stress the importance of training and support on their own terms, recognising autistic differences rather than pathologising them (Bertilsdotter Rosqvist, 2012). A key question in research in transition into adulthood is who is best positioned to provide support and how such support should be delivered (Wilson et al., 2013).
A key question with critical autism studies (O’Dell et al., 2016) is to explore how meanings of autism are being used in different contexts. Informed by a critical autism studies approach, stressing autism as normal and natural in its own right, with both strengths and difficulties, as something which is experienced differently by different individuals and in different contexts, I want to further add the question of what forms of development are to be nurtured and celebrated.

The aim of this paper is to explore different meanings of development and peer support at an autistic-only workplace in Sweden.

**Setting the stage: meanings of age-appropriate peer support and development among people with autism**

In order to ‘set the stage’, at first I will explore different meanings of peer support aimed at autistic people in research. This includes how different meanings of age and development, and certain taken-for-granted notions of autism as (mostly) expression of a ‘pathological development’ (rather than just an ‘alternative’ development, cf. O’Dell, Brownlow, and Bertilsdotter-Rosqvist, 2018) to be treated and cured inform this support.

In research on peer support and development among people with autism, the person who is described as being best positioned to provide support is frequently a non-autistic person. This is the case in developmental support through the autistic life course from childhood to adulthood. For example, similarly aged non-autistic children often function as trainers and support actors for training autistic children in age-appropriate social conduct (Barber et al., 2016; Egel et al., 1981; Harper et al., 2008; Kern and Aldridge, 2006; Kohler et al., 1995; O’Connor, 2016). Similarly aged non-autistic peers are represented as key holders of social development, as socially competent (Kohler et al., 1995), as role models (Egel et al., 1981), and as able to decipher the ‘hidden curriculum’ (O’Connor, 2016). In line with this, activities are often promoted that pair children with autism with non-autistic peers in a diverse range of mainstream settings (Haney, 2012). The inclusion of autistic children in mainstream settings is thus dependent on the inclusionary or exclusionary practices of non-autistic children (Freitag and Dunsmuir, 2015). Several studies have stressed the high vulnerability of children with autism to social isolation and bullying (Humphrey and Hebron, 2015), and support from classmates is an important means of reducing the frequency of bullying (O’Connor, 2016) and is an important protective factor against experiences of loneliness (Lasgaard et al., 2010). However, some studies have shown that the inclusion of autistic pupils has risks for the well-being of ‘regular pupils’. For example, regular pupils are at risk of becoming burned out from the inclusion of autistic pupils (Reiter and Vitani, 2007).

Non-autistic peers as social support actors in different social interventions are also central in autistic adolescence (Trottier et al., 2011; Weiss and Rohland, 2015). Several researchers have explored a diverse range of interventions aiming at teaching social behaviours to or supporting adolescents with autism in order to improve ‘the quality of autistic youth’s experiences with their peers’ (McGee et al., 1984). Adolescents with autism are represented as in need of being provided with the opportunity to interact with non-autistic peers (Hughes et al., 2011), but at the same time supporting social interaction between students with autism and non-autistic peers is represented as challenging (Trottier et al., 2011).

Most research on peer support is centred on the increased participation of children and young people with autism in spaces dominated by non-autistic people, so-called ‘inclusive’
or ‘mainstream’ settings (Egel et al., 1981; Falkmer et al., 2015; Harrower and Dunlap, 2001; Laushey et al., 2009). This ‘mainstreaming’ (Egel et al., 1981) has been regarded as ‘a civil right’ (Harrower and Dunlap, 2001), as a possibility to provide ‘exposure to appropriate social models’ (Laushey et al., 2009), and as the opportunity to nurture ‘appropriate social development’ (Harrower and Dunlap, 2001). Exclusions from such spaces due to the spaces’ inability to offer services and adaptations are seen as a problem (Haney, 2012).

Different environments might be differently challenging to people with autism (Kern and Aldridge, 2006), and environments must be carefully prepared to support effective social interactions (Harper et al., 2008). Carter et al. (2008) note that social interactions occurred more often within small group instructional formats, when students were not receiving direct support from a paraprofessional or special educator, and in elective courses. Diener et al. (2016) explored the development of authentic peer relationships through humour, common interests, physical activities, and playful competition and how a scaffolded learning environment with support from peers and an adult mentor provided opportunities for social engagement.

Some researchers have questioned the imperative of inclusion, arguing that not ‘every child with autism is an appropriate candidate for inclusion in an integrated educational setting, particularly when such placement is full time’, while at the same time they recognise the advantages of inclusion, considering it as ‘an appropriate and desirable option for many children’, but pointing out that ‘integration and inclusion decisions should be made on an individual basis, based on a balanced consideration of students instructional and social needs’ (Myles et al., 1993; see also Mesibov and Shea, 1996).

Some research on peer support is centred on supporting adults with autism in forming friendships and participating in the community (Koegel et al., 2013), including supporting adults with autism in the development of positive self-identities (Aylott, 2000). Social support is sometimes represented as risky and as a barrier to independence and social interactions with similarly aged non-autistic peers. For example, the needs for support ‘may require prompting to complete and transition between tasks or activities’, and here the support might be a barrier to independence as youths with autism ‘become dependent on adults for prompts and social supports’ (Milley and Machalicek, 2012). In discussions around strategies and support to enable inclusion and increased independence in mainstream educational environments, the importance of strategies and support that are not cumbersome and socially stigmatising to the person with autism in relation to non-autistic peers is stressed (Carlile et al., 2013), as well as how to prevent adult support persons from becoming an obstacle rather than facilitating social interactions between children with autism and their non-autistic peers (Feldman and Matos, 2013). Both formal and informal support actors such as parents and teachers are receiving tips from researchers on how to create opportunities for students with autism to find acceptance and develop friendships ‘similar to those of their typical peers’ in order for them to fit into general education environments (Boutot, 2007).

Less frequently explored in research on peer support and development among people with autism is what can be referred to as autistic peer support, where the person providing support is another person with autism. In earlier studies on autistic peer support among children with autism, which mostly took place in closed wards, autistic peer support was used in a passive way, as part of an intervention directed to groups of children with autism.
in particular wards. In those studies and interventions, autistic children were seldom active subjects and were rather passive objects of interventions, for example, by being collective objects of video modelling interventions (Charlop and Milstein, 1989) or by being placed in different kinds of segregated environments together with other children with autism and encouraged to play with each other (Benaroya et al., 1977; Black et al., 1975; Haring et al., 1986). Charlop, Schreibman, and Tryon (1983) explored peer modelling/learning through observation, where low-functioning autistic children modelled high-functioning autistic children. The results of successful autistic peer interventions have been similar to non-autistic peer interventions, including increased nonsolitary play, interaction with peers and adults, exploration, and detachment (Benaroya et al., 1977); improved conversational skills (Charlop and Milstein, 1989); decreased self-destructive behaviour (Jones et al., 1974); and reduced stereotypic behaviour and increased task performance (Haring et al., 1986).

Research on autistic peer support interventions aimed at autistic adolescents and young adults have explored and stressed the positive impact of peer support networks for individuals with autism, enabling participants to give and receive support through in-depth discussion – much of which is centred on the experience of having autism – with other autistic peers. Macleod (2010) stresses that understanding what autism means on a personal level might be an important process for young people with autism, and the importance of being able to reflect on this and discuss this with autistic peers in support groups can be particularly helpful (see also Hillier et al., 2007; Stevenson et al., 2016). This also includes autistic peer support from alternative online social worlds that have been specially designed to enable social interactions and social learning (Laffey et al., 2010).

**Methods and data**

The analysis in this paper is based on data from fieldwork among a group of autistic self-advocates in Sweden, hereafter referred to as ‘the group’. They are working together in a three-year autist-led project aiming at supporting young adults with autism with life strategies and with peer-to-peer mentoring as well as educating employers about autistic abilities. All members of the group have individually tailored work roles and responsibilities in the project. Work roles include teaching, course development, taking care of practical things, managing contacts with social services, performing employer-related group leadership functions, or doing administrative work.

The project offers courses on autistic abilities, aiming at autistic self-development and ‘theme meetings’ organised around certain themes. The work of the group was informed by the perspective of neurodiversity, including the view that autism and autistic traits are to be viewed as part of a normal human variability, where autistic functionality is normal for autistic people, something to be supported and developed rather than to be ‘treated and cured’ (cf. O’Dell et al., 2016).

The group includes four women and three men, ranging in age from their 20s to their 50s. All of them have a diagnosis of autism (Asperger syndrome), and all of them but one had their diagnosis as adults. I was initially invited to the group through the leader of the group due to my previous research engagement, where I had run similar focus group interviews with autistic people in a research project on autistic identity informed by critical
autism studies (O’Dell et al., 2016). My role which me and the leader discussed before and established during those focus groups was to support the group in their self-reflections around both the work process in the project and their development as a work group. My sense of myself was that I was something of a ‘critical friend’ of the group, neither a part nor an outsider of the group. I have not a formal autism diagnose of my own, but I view myself and was viewed by the group as a person with autistic traits of my own. I met the group monthly over the course of two years. Each focus group interview lasted between 1 and 2 hours, and the interviews were recorded and transcribed by one of the participants in the group.

I led the focus group interviews, and my role in the interviews ranged from being a passive listener and questioner – listening to what was said and asking questions in order to facilitate the discussion or move it further towards themes I found interesting – to being a more active participant by providing analytical suggestions or interpretations of what was said. The focus groups always started with ‘What has happened since the last time we met?’, and from that the discussion swung back and forth in directions that both the participants and I found interesting. Participating in the focus group was voluntary, and the whole group did not participate every time, but most times the focus group included the majority of the group members, and several of them told me they found the discussions interesting and fruitful in their work within the project. My sense is that the focus groups – including my questions and interpretations – functioned as a reflection space for the group and encouraged them to reflect upon their work and what current processes they were engaged with in their work. The atmosphere during the focus groups was both intensely focused on the themes being discussed and relaxed and friendly, and people joked and laughed a lot.

In approaching the analysis, I was looking particularly for examples of markers of support for autistic people. During this phase of reading and re-reading the data, two central meanings of support emerged – autistic peer support and non-autistic professional support. Closely connected to the different meanings of support were notions of development and what the group found to be central in acknowledging and nurturing particular forms of autistic development, including ways of learning among people with autism. From the inductive analyses of data, I got interested in contrasting this in relation to previous research on autistic development and peer support aimed at autistic people. My approach to the analysis was guided by the framework for thematic analysis suggested by Braun and Clarke (2006). My preliminary analyses were presented to the group in order to get their comments. This was done at a group seminar, where I provided the group with mind maps on different themes (among them support) I had done based on both my own preliminary analyses and on preliminary analyses made by one of the participants of the group (who also did most of the transcribing of the data). Those mind maps gave a broader overview of all the focus group interviews, a more overall mapping, which the groups found interesting to discuss. The theme support was among the themes both me and the group found most interesting. This is the reason while I choose to work further with it in this paper. I took notes during the discussion during the seminar and those notes have informed both the final analyses and the conclusions. The leader of the group has read a final draft of the manuscript and approved.
The members of the group spoke of themselves by preference as ‘autistics’ for the purpose of emphasising autism as an essential part of their personality, including a definition of autism that included both difficulties and abilities, but also in order to stress solidarity within the autism spectrum (not making a distinction between more or less able people with autism and instead stressing similarities in ways of functioning), and thus this term seemed more appropriate than ‘people-first language’ (for a discussion see, for example, Sinclair, 2010). In the present article, when I refer more generally to the group of autistic people regardless of their identity I use people-first language, but when I refer to the participants or the narratives used among them I use the participants’ own preferred terms.

Findings

In the beginning of the group’s project and during the first focus group interviews, a recurring theme that was discussed was the differences in autistic and non-autistic ways of functioning, as exemplified by narratives of experiences among non-autistic formal support actors trying to support autistic people. Non-autistic formal support actors were described as focusing on hardships and difficulties in working with autistic people, including a sense of not knowing what to do:

Oscar: We were told by the Employment bureau, there was one [employment officer] who just started talking about how nothing was harder for an employment officer than working with an autist. And this was especially the case when they had assigned an internship or work or some kind of job. They said how the autists don’t show up, how they don’t call when they’re sick, how they don’t attend predetermined meetings, and other such things. And how it was really a big problem for them. ‘We do not know what to do with them [the autists]’. They said this straight away.

The non-autistic formal support actors were described as resigned and as experiencing autistic young adults as being so passive and withdrawn that the employment services do not know what to do with them. At the same time, an unequal power relationship between autist and non-autistic support actors was stressed.

Oscar: Then there is a relationship between the Employment bureau and the social insurance and the autist, uh, it’s a vertical, uh. You sociologists speak a lot about that. The vert … No, okay, but forget it.
[Author]: No, I do not know. Hehe.
Oscar: The vertical, no, okay. There is a perspective from above. For I feel that when Alice and I went to the Employment bureau, it was the first time I walked into the building without feeling any anxiety. I had always been coming there as a very small man, as is the case for everyone who uses them, or at least for most. And then you get there as one [colleague] and about to talk with colleagues there. It was something completely new. And when you do get well acquainted with them, you might also point out to them that this is how the autist feels, maybe even more strongly than anyone else.

In relation to the difficult encounters between non-autist support actors and autists, the meanings of autistic peer support gradually took form during the focus group interviews. Central in autistic peer support is the ability to understand, and a primary expression of this understanding is the notion of ‘the bubble’.
When the group talked about the notion of a sense of being locked-in, the ‘bubble’ was a central part of the formulation of the problem. Being locked-in was also described as the opposite of development. The solution was to be able to get out of the bubble through coming into contact with other people, and through this enabling a developmental process through experiences. Being locked-in was described as an effect of both autism and institutional locking mechanisms. Expressions of both institutional and individual autistic locking mechanisms included economic subsidies – either from the social services or from parents. These subsidies support young adults (up to the age of 30) who, due to different kinds of difficulties, have problems in moving on in their lives, including problems with getting and maintaining employment in the regular employment market. Having this economic security might lead to a false sense of security as well as to a belief that one is not able to work, and having autism-related difficulties in imagining the next step or other possible situations might lead one stay in the current situation even if it is not something one wants.

Alice: And we have an extremely strong need to actually be out there and learn, because we learn from what we see and what we experience. And so, ah …

Lilly: Mmm

Alice: We cannot conceive or imagine or just pick up from others what they seem to convey to us.

Oscar: Mmm.

Alice: We have to have our own experiences, and you can’t get that if you are just put on a [disability] pension.

Other locking mechanisms include different formal and informal non-autistic support actors, such as professionals and parents, who function as interpreters of autistic peoples’ needs and who try to talk on behalf of autistic people.

Alice: (…) But then it’s, well, it’s much about the attitudes in the environment toward young people then. And they’ve got somebody or some, they have [me] told that, for example, uh, you’ve got difficulties with, and it is the autistic, that sometimes one has difficulties with sleep because one worries too much, and then one has difficulties with time and there is stress and things like that then. When you do not fit in. And this is perceived by the environment that you are lazy and disloyal and that you cannot function. And then there was a guy I was talking with, he said, spontaneously after a while, ‘Well, and then I might be lazy or something, but it might not be true, but some people have told me so, so I believe it’. *laughs* *(someone: Mm.)* So he began to sort it out there himself a bit. *laughs* * But it is there as well, it is what we think this course is for, it is to find strategies to be able to, to not get stuck in those downward spirals, but to have the strength and opportunity to do things.

Several participants in the group referred to similar experiences of being misunderstood by their environments. This included experiences of hearing that they either were lazy or were too high functioning to be autistic or – as a consequence of an early diagnosis – getting an assistant and going through one’s whole elementary education with the sense that one has significant difficulties and must get used to always being taken care of and never being challenged and forced to learn and to have experiences. Oscar referred to such a situation as being a risk for prolonging the childhood development stage of life. In relation to
receiving a diagnosis as an adult, including the need to manage different difficulties on one's own, Lilly recalls:

Lilly: That is so hard, that question you almost always get when you are out and lecturing or something, that 'Do you think it would have been better if you received your diagnosis earlier?' and 'Would it have made a difference?', and so on, and it is both yes and no. I received it when I was about 20, so I had gone through school, and in a way I'm glad I did it, because then I had to do it in a completely different way. It was really tough, and it led to a collapse in the end, but I probably would not have wanted to receive a diagnosis when I was maybe 12, because then you would have received support all the way, and then you wouldn't have the same opportunity to, well, to try yourself or to test what you can and cannot do. It's so easy to just say, 'Here, you get all this support', 'Well, I'll take it then, how convenient that was'.

Alice: It's like constant surveillance almost.

Lilly: Yes.

Alice: And others might try to think for you or to control you, thinking they know a little better.

In relation to such non-autistic support that might result in overreliance on support rather than developing strategies and skills that are important for a more independent life, the group stressed autistic peoples' alternative ways of developing. For example:

Lilly: We tried to show them that you can buy a calendar, but they did not really understand the point of it because 'that is something that just happens on its own. I don't need to think about that'.

(...)

Alice: Well, yes, they do need something like that, to strengthen up and like, uh, uh, to get out into the community and into a job, and this is where you need some other tools than just people who are not autistic. Just because we think differently. We mature in a different way, and we, use it and just see, well, you know yourself better and what it is that you can do on the basis of how you are. And I think this is missed totally, and it is really this, that we can say that when we talked to the social insurance service and the Employment bureau, they really saw that what we offered, what we're talking about, they are lacking. It was a piece of the puzzle that they didn't have, but what really is needed.

In relation to non-autistic formal support actors' sense of not knowing what to do, the group stressed that autistic development and ways of learning are different from non-autistics. This calls for alternative supportive strategies based on autistic ways of functioning.

Oscar: And I know from, in the association [Organized Aspergers] when I have talked, I've had many social conversations with people, that this is a big problem. There was one here in [Middletown] who lost his job because of this particular thing. A relationship ended and he became bedridden for a week and could not get up to call. And then when he gets up he was told by the Employment bureau that, uh, the workplace had terminated his job. And, uh, then the question is, how typical is this for autists, or is it typical for young people, but, but, then at the Employment bureau, then it was this big thing that they could not convince them, or they did not know how they would tell the autist that you must call.

[Author]: Although you may not understand the point in calling.

Oscar: No.

[Author]: So 'why should I call?'

Oscar: Ah.
‘What is it for really?’

Alice: I would say it like this. I have been involved in similar things, and that’s, uh, if you yourself think that you’re that autist then, like, you, it [the energy] just runs out then. Then it is, then one can be so, eh …

Oscar: Mmm

Alice: Well, you do not have the energy, you cannot, you don’t have the strength of even saying and explaining what it is that is the problem. Because, uh, you become terribly weak when, uh, when you feel bad. Uh, and what I have noticed that can help out, that can help this, it is absolutely essential in this situation, it is to get one, to get out a message that I am ill, that something has happened to me. I cannot do what you expect of me. And I have been thinking that when something like this happens, there should be a person, a person one can always contact even if it feels bad and things like that. And it must often, it must be a person who maybe is autistic themself, or perhaps who has total, complete understanding of where this person is, and does not ask extra questions, and does not stand there and say they don’t understand, but someone who is autistic and can take this and pass on this contact, so you need some kind of such support.

This particular support system strategy (such as an ‘autistic help line’ or an ‘autistic pilot’) needs to be carefully prepared in advance so that it is available when situations arise, and it must be adapted to the individual’s way of communicating. There can be no hint of condemnation because this might risk increasing the person’s sense of self-questioning and doubt, resulting in a negative spiral of problems and to the inability to perform certain tasks such as informing the employer in the right way about sick leave. Such questioning and doubts could cause the person to back even more into their shell until the whole thing has escalated and the person loses their job. Due to executive difficulties such as difficulties with starting an activity, the several steps in informing the employer in the right way rather than in just one step might be too difficult, and autistic support people might see this and be able to tell the employment service what the problem might be in a situation involving an autistic employee or trainee.

Part of autistic peer support is a focus on abilities and interests rather than on difficulties, including identifying as autistic and embracing autistic development. Hearing all the time about one’s difficulties and being overly supported might become a barrier in one’s development and prevent one from moving forward in one’s life:

Alice: And that is the tragedy of this, it is that … that, with these, early retirements [financial support to young people with disabilities] that last until their thirties, and well, after that we’ll help. It is also a very good, or not good, but it is after all, having a strong lock-in effect. Because this makes it such that this person does not really get started with some work and stuff, but has a disability pension until they are thirty. And they cannot be trained or, well, developed. And it’s super sad because autistic people need to develop, well, they need to discuss, analyse, get, uh, be involved. Because we have poor ability to imagine, we need to, we need to have concrete experiences with things. And, if we are to understand this with different social settings and stuff, then we must be in social contexts. Uh, and we don’t learn, only like this, intuitively by seeing how others do it, or through intuitive learning from one’s environment, but we have to analyse and consider. And then we have to be part of that as well, we cannot be locked out from it.

Oscar: No.
Alice: And, then, if you do not get this. A system can pretty much be [closed], that it is very difficult to get into the community as a young person. And that means, that then one just, one just gets more and more disabled. So it’s, it’s the system itself that is crippling people.

[Author]: Hmmmm.

Lucas: There’s something called to mimic well.

Oscar: Mm.

Alice: There’s something called mimicking, and there are a lot of autistic people who have developed an extremely good ability to mimic. Uh, the problem is that, when they have imitated too much, then they do not know where they are or who they are.

Central in autistic-led support is the formulation of support needs, but also the need for increasing self-knowledge as part of development. The discussions around the revision of the course within the group’s project stressed the importance of giving the participants strategies and tools aiming at supporting their development. This included supporting the participants in exploring what their interests and abilities are (seeing what they like to do might be part of discovering what they are good at, that their particular strengths are connected to what they like to do) because such knowledge can be used as the basis for strategies for formulating a professional work identity, for being able to move on in their lives, and for increasing a general sense of ability and self-determination in their lives.

Conclusions

Ideas around who is best positioned to provide support and how such support is delivered must be understood in relation to what kinds of development are to be nurtured and celebrated. In research on peer support for people with autism, ideas of development are connected to non-autistic development, and therefore to non-autistic people as support people and as role models to people with autism. In this paper, I have explored ideas of an alternative autistic development to be nurtured and supported by autistic peer support. Solomon (2015) has argued that certain types of social interactions within non-autistic social worlds might either facilitate or hinder the sociality of people with autism. She illustrates this with how the bodies of children with autism are manipulated, managed, and constrained in response to the perceived deficiencies inherent in the children’s behaviour by non-autistic peers, institutionally authoritative adults, and parents (Solomon, 2015). Solomon further argues that in some such interactions, such as in interactions with dogs, children with autism might be more social than in others (2015, 339).

To learn to successfully pass as non-autistic, through training and interventions, and to become ‘indistinguishable from their peers’ (Leaf et al., 2011) might mean that autistic people learn how to act as non-autistic people but do not really learn about their own ways of functioning and ways of developing and learning.

Formal and informal support actors might reinforce institutional and individual autistic locking mechanisms through support that is not based on understandings of autistic functionality and ways of developing and learning. The meanings and aims of autistic peer support have changed. While autistic peer support in the early 1970s and 1980s meant being in separate settings and being regarded as passive objects of collective interventions aiming at nurturing non-autistic ways of development,
recent research has explored autistic peer support as a way of strengthening self-
knowledge and sense of identity by valuing autistic differences. This, though, is
done in less formalised ways, such as informal support groups in offline and online
spaces (e.g. Hillier et al., 2007; Laffey et al., 2010; Macleod, 2010; Stevenson et al.,
2016). Spaces for nurturing and exploring autistic ways of functioning risk becoming
parts of isolated islands rather than ideas informing support oriented at autistic people
in general. Questioning the exclusivity of both formal and informal non-autistic
support, the group in this study argues for the importance of more structured and for-
mulated formal and informal peer support led by autistic people, aiming at autistic
development on autistic peoples’ own terms and informed by notions of autistic devel-
opment as merely different from non-autistic development rather than as pathological.
This includes a way of learning based on having experiences yourself. This is con-
trasted in the group with narratives about young autistic people being locked in
well-meaning formal and informal support systems and support actors. These are
often barriers to developing independent behaviours and nurturing a sense of adult
responsibilities, including economic independence from the social welfare system
and parents. This stresses the importance of receiving adequate support from both
non-autistic and autistic support actors through interventions that are based on the
autistic person’s ideas of autistic ways of developing. This includes support in execu-
tive function, in formulating goals and future aspirations, in getting to know one’s abili-
ties, in embracing and cherishing one’s strengths and interests, and in getting to know
one’s difficulties, and it includes strategies to manage one’s difficulties without reinfor-
cing a sense of failure.

Disclosure statement
No potential conflict of interest was reported by the authors.

Notes on contributor
Hanna Bertilsdotter-Rosqvist is an Associate Professor in Sociology and currently a Senior Lecturer
at the Department of Social Work, Umeå University, Sweden. Her recent research is around autism,
identity politics and sexual, gendered and age normativity.

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