# Friendship and sociality in autism services

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## Editorial comment

This paper explores the notion of friendship for autistic people supported by staff working within a range of services set up by Scottish Autism. A research team within the organisation interviewed adults, held focus groups and took part in social groups. Although small scale, the findings suggest that autistic people may define friendship differently from typical people and that they enjoy activities where they can choose to interact with others or take time out and be alone. Some view the staff as their main (or only) friend. The latter raises important questions, rarely explored, relating to friendships between staff and those they support. What are and should be the boundaries and expectations for both the autistic person and the staff concerned? The Editor would welcome papers which explore this topic further.

## Introduction

The diagnostic characterisation of autism as a difficulty with social interaction has often led to stereotypes of autistic people as asocial. These stereotypes have been critiqued in a range of first person, familial and research accounts that report strong and meaningful social attachments by people on the autism spectrum. However, the process of making and maintaining friendships, particularly given normative ideas about what constitutes friendship, can remain challenging and anxiety ridden for many autistic people. By recognising the many ways in which people associate with one another and form social relations – what we refer to here as diverse sociality – we argue that alternative forms of friendship and meaningful attachment can be recognised and nurtured among autistic people supported in services.

This paper reports on a practitioner research project on friendships and social opportunities within specialist autism services run by Scottish Autism. The organisation provides a range of support for autistic people

throughout the lifespan. Its research programme aims to inform practice development through critical reflection, grounded in systematic enquiry. Through practitioner research (Mitchell, Shaw and Lunt 2008; Shaw, Lunt and Mitchell 2014), practitioners address questions arising from day-to-day support in social care, outreach, and education services with the meaningful participation of supported autistic people. This can also be seen as a form of 'action research' (Altrichter, Posch, and Somekh 1993; Whitehead and McNiff 2006) in that the project aimed to inform future practice through answering these questions.

Following discussions within our own research team, which constituted a critical 'community of practice' (Wenger 1998), the team promoted dialogue and reflection on friendships and social interaction through a workshop attended by 45 support practitioners working within Scottish Autism's services. These range from outreach services for autistic people who live independently, to supported living and day services for people with

additional intellectual disabilities or high support needs. In such contexts, recognising and nurturing friendships needs to take account of the vastly differing needs, perceptions and manifestations of friendship among autistic people supported in services. Data presented in this paper comes from focus groups and interviews with both staff and supported autistic individuals to gain different perspectives on friendships and social opportunities in services. Participant observation was also carried out by members of the research team within dedicated social groups for autistic adults. The methods used and questions asked are given in *Appendix 1.*

## Autism and friendship

Friendship is usually characterised as a relationship of affect, reciprocal support and companionship (see for example, Bukowski, Hoza and Boivin 1993; 1994). A small but growing body of research into autism and friendship has emerged over the past two decades based on this characterisation. Several research studies have sought to assess the quality of friendship among autistic people using established tools such as the Friendship Quality Questionnaire (Parker and Asher 1993) or, more commonly, the Friendship Quality Scale (Bukowski, Hoza, and Boivin 1994) in which autistic participants score their satisfaction with companionship; security and intimacy; closeness; help and conflict (eg Whitehouse et al 2009; Bauminger and Kasari 2000; Bauminger et al 2008; Calder, Hill, and Pellicano 2013; Rowley et al 2012; Chamberlain, Kasari, and Rotheram-Fuller 2007; Sedgewick et al 2016; Whitehouse, Durkin, Jaquet and Ziatas, 2009).

A systematic review of the topic demonstrates that autistic people report lower friendship satisfaction across these scales than their non autistic peers (Petrina, Carter, and Stephenson 2014). In particular, these research studies note difficulties with social reciprocity (see also Carrington, Templeton, and Papinczak 2003). It is important to note, however, that the friendship definitions used in research have often been normative, that is, they use a model of 'typical' friendship, in particular 'best friendship' against which autistic participants' experiences are compared.

In a study of social networks within inclusive classrooms, researchers found that autistic pupils were often on the periphery of social groups (Chamberlain, Kasari, and Rotheram-Fuller 2007). While those pupils felt themselves to have friends, those friendships were not nominated reciprocally by non autistic peers. Nonetheless, those same pupils reported low levels of loneliness and largely similar levels of friendship quality to non autistic pupils. Similar observations were made in a multi-informant study by Rowley et al (2012). It might therefore be considered that presence within a community and sense of belonging might provide meaningful social ties and fulfilment to autistic participants, even if their designation of community members as friends does not conform to a dyadic model of friendship, or involve intensive or intimate interaction.

Acknowledgement that autistic ways of relating to others may not always conform to normative understandings of friendship has gained an increasing focus in recent research. Two studies illustrate that engagement in shared activities and interests is important to autistic adolescents (Daniel and Billingsley 2010; Kuo et al 2013) while Calder et al (2012) noted that autistic children in their study valued companionship over close, emotional or affective bonds and that time to be alone, away from intensive interaction was also important to some autistic pupils. Brownlow, Bertilsdotter Rosqvist and O'Dell (2015) argue that increasing autistic engagement in online social networking and the advent of explicitly neurodiverse spaces should be used to challenge dominant definitions of friendship.

## Supported autistic people's perspectives on friendship

In order to gain perspectives on friendship from autistic people supported by Scottish Autism, the practitioner research team undertook individual interviews with five autistic adults who attended the organisation's social groups. Researchers also raised questions from the project in a weekly talking group for five autistic adults that takes place within one of Scottish Autism's services. With participants' consent two dedicated group sessions were recorded, serving as focus groups centred on the theme of friendship.

Comments from both the interviews and focus groups reflect how heterogeneous the participants' notions of friendship were, even among a small number of autistic adults. Views of friendship and what made a good friend included:

> "Friends are very good. They help out.
> They understand what I'm coming from
> and I understand what they're coming from".
>
> (Alan)

> "Well they're always there for me and comforting.
> I can trust them. And, well, part of friendship in
> a way is they've been with you all the time, like
> from the beginning".
>
> (Doug)

> "Somebody who can talk to you and share the
> most inner secrets with ... and not trying to report
> it to the [service staff]".
>
> (Gordon)

For the adults in the talking group, much like the participants in the research studies cited above, friendship was defined by the activities that they shared with friends. They said:

> "Someone you can go to Costa with and
> have a coffee".
>
> (David)

> "Someone you can go to the pub with".
>
> (Roy)

Staff who attended the practitioner workshop noted that friendship for those that who were interviewed was not perceived as radically different to friendship as understood by non autistic people. Yet two points are worth noting. First, the friends whom Doug described were in fact a number of soft toys that he has had for many years and which he finds comforting to have around. While this might not fit a received idea of 'real friendship', the term was very real to Doug. Secondly, there was ambiguity around the friendship status of support staff. For Gordon, friends were defined as distinct from support staff – they are people who would not record and write things down in the way that staff do. Conversely, when Roy was asked who his good friends were, he named only support staff with whom he had built strong relationships over the years.

## Staff perspectives on friendships within services

While the individuals cited above were able to articulate clearly their definitions of friendship, recognising and nurturing friendship among those autistic people that find it difficult to reflect in this way remains important. The practitioner research team therefore conducted four staff focus groups in different locations. A total of 21 staff took part. The dialogue was recorded and two members of the research team undertook a thematic analysis of the material guided by the work of Braun and Clarke (2006). Key themes and observations from the focus groups are given in *Table 1*.

Staff reports of loneliness, limited social opportunities, difficulty with making friends and problems in reciprocal relations, chime with the research literature cited above. It is notable, however, that some staff recognised meaningful relationships and forms of social attachment between autistic individuals that do not necessarily conform to a normative definition. Engagement in social media, and close working relationships with staff were both reported as having positive and negative consequences. As the research literature suggests, online social networking can provide a means to socialise beyond one's immediate locality and mitigate isolation. However, social media can also create confusion in contexts such as Facebook where every acquaintance is designated a 'friend'. Staff reports of tensions and ambiguities around whether they could be considered friends highlight strong and affective attachments that staff and supported autistic adults may have, creating difficulties in navigating professional boundaries.

**Table 1: Staff perspectives on friendships in autism services**

| Identified theme | Indicative comments |
|---|---|
| Some supported people want to make friends but are unsure how. | "Peter just now is desperate to make friends and it has become the focus if his day. He will say: "I want to be Steven's friend, I want to know how to be Steven's friend.""<br><br>"Almost everyone I support says they want more friends but when it comes to doing things to make friends, like going out, it's really challenging." |
| Some supported people lacked meaningful social opportunities | "Prior to [joining the current service] there was no-one around John. He went home and spent his time alone in his room for hours and hours. In the unit he spent most of the time on his own."<br><br>"The social club was being run like a youth group ... It didn't feel like a social group where people could interact or have opinions. You need a good staff team to facilitate things, but really let the people run the group and direct activities rather than being told by staff what they are going to do." |
| Some supported people have difficulty with social reciprocity | "Sometimes they don't understand it's a reciprocal thing – they think more about 'what a friend can do for me' rather than 'what I could do for a friend'. They may not understand their responsibility in a relationship."<br><br>"If there is a disagreement, they instantly say the other party is no longer my friend. They think a friend has to think the same way they do." |
| Supported people display meaningful social attachments within services. | "John was working on the computer and he printed something out. He printed one out for all the others, and when asked why, he said "for friends"... because he has done other things with them, he perceives they are friends."<br><br>"I think they are friends because when he sees him his face lights up."<br><br>"He found it difficult when another service user had left the service. They used to do things together... you could tell that he missed the other service user." |
| There are difficulties navigating relationships and boundaries between staff and the adults they support. | "Some of them may see staff as friends, and you have to explain that it is different, that you are there to support them."<br><br>"Some of the staff working with him in the team I had at the time, he was wanting to class as friends and he wanted to get in touch and have a chat at the weekend and things like that. I felt really cruel sometimes. You had to be really blunt."<br><br>"It is a difficult one because you are spending masses and masses of time with them. You are gaining their trust, you're caring for them; you are having fun with them. You build relationships and everything."<br><br>"I keep in contact ... I think that it is important if somebody has known you for 8 or 9 years." |
| Social media creates both opportunities and tensions. | "It's a different view on friendship (eg chatting online) and Facebook too – they think they have friends but there is a very remote connection."<br><br>"Facebook has two sides to it because what can be written can be taken in so many different contexts... It can go both ways. Facebook is also really good because it gives them time to think about what people are saying and process it."<br><br>"Some of the service users have sought advice because they have not been accepted as friends on Facebook (by staff) ... It is hard for them to understand why we can't be their friend." |

## Reflections on social groups

During the course of the study, practitioner researchers participated in two adult social groups run by Scottish Autism in order to better understand how friendships might be nurtured in services. The groups were attended by autistic adults who lived independently as well as those receiving regular support services. The groups sought to provide social opportunities for individuals that might be vulnerable to social isolation and wished to make new friends. Practitioner researchers from the project team attended the groups as participant observers joining in with activities and reflecting on the group, together with staff and participants. The team also conducted interviews about friendship and social opportunity with five regular attendees.

The idea of an autistic social group is something that some people on the autism spectrum feel ambivalent about if they feel they are being pigeon holed, labelled or limiting other opportunities for socialising.

As one interviewee explained:

> Doug:   *"I was sceptical about going in the first place because I thought I was giving myself a label by going there."*

> Interviewer:   *"That's something it's important for you to avoid, do you feel?"*

> Doug:   *"Yeah, I try not to think about it too much. I try to be myself."*

However, another social group member, Simon, was very clear about his preference for socialising with others on the autism spectrum rather than non autistic people:

> Interviewer:   *"Do you prefer socialising with your autistic friends compared to say, a group of people who are not on the spectrum?"*

> Simon:   *"Yeah I do.  As I said, I just feel we have more in common and familiarity. I just feel they understand me more compared with people who are neurotypical."*

These different feelings about autistic social groups simply underline the need for individualised services that make such groups available for those that find them valuable, but also that support access to other forms of community participation and social opportunities for those who are less comfortable with specialist groups.

The social groups undertook a range of activities including cookery and communal meals, walks, bowling, swimming, pub quizzes and comedy shows. What practitioners and autistic participants in both groups cited as helpful were activities in which participants could drop in and out, and where they could engage in different degrees of social intensity. One attendee explained that she enjoyed the cooking activities as there were opportunities to be heavily involved in the cooking and chatting in the kitchen area, but also the chance to drop back to the periphery and sit quietly at a table without feeling pressured to interact.

A group coordinator reflected on swimming groups having a similar structure whereby participants could huddle and chat or go off for a swim if they wanted a break from socialising. In another group, participants could be involved in games of pool while others were content to find a quiet space to play computer games or just sit on the periphery. A group coordinator talked of the group dynamic as one of 'waves of socialising'- moments of togetherness, intense interaction and joint focus interspersed with quieter times in which members could retreat from such intense interaction. In both groups, staff and participants emphasised the need to provide a mixture of structure and freedom.

In both groups, participants reported friendships formed within the group that continued outside the meetings. Although initially dubious, Doug formed a firm friendship with another member of his group and the two now regularly meet outside the group that he attends. Other members reported meeting socially to go to the pub and the gym. In one instance the participants then felt that they no longer needed to attend the group and wished to meet informally outside, while others preferred to stay within the more structured and routinised environment of regular group meetings. In all instances, participants felt the group to be an important catalyst to these friendships.

## Discussion

In thinking through the many ways in which people supported in autism services relate to those around them and form meaningful social bonds, useful points of departure can be found in the literature of social anthropology as well as in the concept of neurodiversity. Ochs and Solomon (2010), two anthropologists who have worked extensively with autistic people, argue that:

> "human sociality consists of a range of possibilities for social coordination with others, and autistic sociality is one of these possible coordinations." (page 70)

In view of this assertion, it stands that support staff can nurture meaningful relationships and social opportunities for autistic people if they are able to recognise and nurture the diverse ways that people enjoy being together. The focus group data suggest that some practitioners noted difficulties with reciprocal interaction and making friends among adults they supported. Others, however, were able to identify alternative ways in which supported people formed bonds of friendship: in choosing to be together; in printing out documents for one another; or in recognising affect in facial expression. Reflections on social groups underlined the need for safe spaces where different forms and intensity of social activity could be facilitated.

The practitioner research team felt that in order to validate and nurture meaningful relationships between individuals it is important to encourage and educate staff to broaden ideas about what constitutes meaningful interaction and friendship for autistic people. This, in turn, may mitigate some of the reported anxieties that autistic people feel to meet a normative definition of friendship.

There is a danger that defining 'autistic sociality' or 'autistic friendship' (Brownlow, Rosqvist and O'Dell, 2015) too distinctly might reinforce a binary opposition between autistic and 'typical' sociality. Instead we argue for the need to recognise diverse forms of sociality in services. This echoes the language of neurodiversity taken up by the autistic self-advocacy movement that sees autism and other neurodevelopmental conditions as differences, rather than disorders, and recognises and celebrates diversity among all humans (see eg Kapp, Gillespie-Lynch, Sherman and Hutman, 2013). Developing an organisational discourse around 'diverse sociality' could encourage staff to think imaginatively about providing opportunities that enable autistic people to enjoy being with others and to form meaningful relationships whatever form those relationships may take.

Autistic adults who spend their lives in supported living environments can develop strong relationships with the staff that support them. Staff are omnipresent in supported peoples' lives, often spending a great deal of time with them and engaging in everything from leisure activities and holidays to emotional support at times of crisis. Relationships develop over long periods of time and often involve affect and trust. It is therefore not surprising that both staff and supported autistic people expressed ambiguity about whether staff could be considered friends. While many staff reported the professional need for distance, and policy guidelines do exist, these relationships are little understood or discussed in autism research literature. It would be helpful to develop research that takes account of the individualised, community based service contexts in which many autistic people are supported. The relational nature of those services deserves greater attention given the positive and negative implications of social relationships on the wellbeing of supported individuals.

## Concluding comments

The project reported here provided an opportunity to gather a range of perspectives and observations on friendships and social opportunities in autism services. This inspired practitioner researchers to think critically about friendship, social opportunities and diverse sociality within the services.

In summary, practitioner researchers found that:

- Some support staff recognised difficulties autistic people had in maintaining friendships based on social reciprocity. However, other staff observed alternative forms of sociality and interaction that appeared meaningful to those they support.

- Autistic individuals differed in their attitudes to dedicated social groups, but several found value in the company of other autistic people and have made friends through social groups set up by the organisation.

- Both staff and autistic individuals that they support report ambiguity and uncertainty about the social attachments formed between them in the course of day-to-day support practice.

On the basis of the findings, the authors propose that:

- Staff are encouraged to take a broad, non-normative understanding of friendship and sociality in order to recognise and nurture meaningful relationships and social experiences for the people they support.

- A clearer account and understanding of relationships between staff and autistic individuals in support services is needed to understand how these relationships might be better managed and how they impact upon the wellbeing and life experiences of supported autistic people.

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# Appendix 1: Research methods used and questions asked

## A  Interviews with supported autistic people

Interviews were semi-structured and, as such, included follow-up questions relating to responses given by an individual. The basic interview framework contained the following questions, which could be drawn upon, adapted or used selectively with individual participants. Prompts are included in brackets.

### Questions on friendship

1.    Which people in your life do you spend most time with, and who do you consider
most important to you?

2.    What is your definition of friendship?

3.    Is there someone you would consider a good friend?
(If so, why? How do you know what a good friend is?)

4.    Do you have one good friend, or specific friends for specific interests and activities?
Where did you meet them?

5.    Do you find it easy or difficult to make friends? (Why?)

6.    Do you ever feel pressured to have friends?
Do you have any worries or anxieties about having friends?

7.    Do you have any friends that you communicate with on the internet?
How did you get to know them? Have you met them in real life?

8.    Do you think that your autism creates difficulties in having friendships?

9.    Do you have other friends with autism/Asperger syndrome, or friends who don't, or both?

10.   Do you like or prefer socialising with other people on the autism spectrum? (if so, why?)

11.   (If relevant) How do you find having friends who don't have Asperger syndrome/autism?
What do you like/find difficult about this?

### Questions on the social groups

1.    What made you want to join the Scottish Autism Social Group?

2.    How long have you been going?

3.    What do you feel you get out of the Scottish Autism Social Group?

4.    How do you feel about the staff presence at the social group?
(Do you find it helpful to have staff around? What do you find most helpful or difficult?)

5.    What activities at the group do you like best? Why?

6.    Is there anything you would change about the way the group is run?

7.    Do you have any particularly good friends in the group?

8.    Have the social group or other services allowed you to make new friends or maintain friendships? (If yes, please tell us about it.)

9.    Have staff helped you with this? Could they support you more?

10.    Apart from the social group, what other social activities do you like to do?

11.    Are you in any other groups, clubs or workgroups that you enjoy? What do you like about those?

## B  Talking group/focus group with supported people

The two focus groups took place within a regular talking session in which two of the practitioner researchers were involved. The discussions were recorded and transcribed on these two occasions with the full consent of participants. The discussions were based around words or phrases printed upon pieces of paper. Participants then shared the thoughts and associations inspired by these words or phrases. At times these cue sheets were placed in the centre of the group with everybody contributing. At other times, turn-taking was encouraged by passing the pieces of paper around for each person to comment upon. Concepts for discussion included: 'people that are important to me'; 'places that are important to me'; 'activities that are important to me'; 'friends'; 'staff' ; 'care' ; 'support'; 'community'.

## C  Staff focus groups

Staff focus groups were initially part of a broader investigation that addressed issues of friendships, relationships and sexuality among supported people. The discussions were recorded and transcribed and sections relating to friendship and social opportunities were identified and used for thematic analysis. The relevant question prompts were included below. It should be noted that as focus groups are intended to be open ended and discursive. These were simply starting points for conversation and often led to further questions and prompts in individual groups

**Questions: Thinking about friendships within your services:**

1.    What do you think friendship means to the autistic people that you support?

2.    Do you think that friendship among autistic people might differ from that of others or not? Can you give us any examples from your services?

3.    Can you think of any instances within the last year when autistic service users have requested, or needed, support in making and maintaining friendships and, if so, what kind of support is required?

4.    What are the challenges in supporting autistic people to make and maintain friendships?