

Pub Night: Life History of a Peer Support Group of Young Adults with Autism in Rural Northern England

Melisanda Berkowitz

Chukyo University

Author's note:

I am employed by Chukyo University in Aichi, and this academic year I have had the privilege of spending a year on sabbatical in the UK. My research has focused on how parents of young people with learning disabilities negotiate and advocate for their children's transition to adulthood. An in-depth comparison of the situation in Japan and that in the UK is beyond the scope of this article, but I hope readers will note both similarities, differences, and implications for peer support activities in Japan.

Abstract

Peer support is a flexible strategy used for a range of people and purposes. In this article I introduce a peer support group used by people and families with autism to mutually connect, noting the group's link with advocacy for wider autism awareness and more effective social support. Initiated as an informal parents' support group, it has evolved with the changing social and policy context. It now meets at night in a local pub, and the core members are those with autism rather than their parents. Linked with national policymaking through its founder, the group is also involved in coproducing more effective disability care. This article retells the group's life history based on an interview with its founder, and analyses the group's achievements.

Introduction: No Flashing Lights and No Stigma, Just Friends at the Pub

If you find yourself in Kendal, Cumbria on the second or fourth Thursday of the month, the pub to head for is the Wakefield Arms. Locals, business travelers, couples, and in one secluded corner, a mixed group of 15 or so, with a wonderful, gently joyous buzz. They'll welcome you, whoever you are, even if you are not on the autism spectrum.

You've come to the twice monthly meeting of the South Lakes Autism and Aspergers Group. Their ostensible reason for getting together is for neurodiverse adults to give mutual support in navigating the challenges of the neurotypical world. According to founder and parent, Sally Percival, the group has been more successful than she ever imagined.

"The best thing about it is the natural friendships that have formed. For example, one young man rang me about two years ago now. His mum came to the support group when it was more of a parent support group, but I hadn't spoken to him for 15 years. And he rang me very depressed, had absolutely no friends at all, he did nothing with his life and just wanted to come along to the group. He was very frightened, so we agreed to meet outside the pub and go in together. Anyway, everyone welcomed him in,

and within six months he had a best friend from the group. The two often meet up at the group, have a meal and then when we all leave at nine o'clock they go out to jamming sessions, on a weekend they see each other, and he's now so busy that he often doesn't come on Thursday – which is such a success... So there are lots of genuine friendships from the Thursday night meetings. I don't think you can really plan that sort of thing – it just happens organically. And also, they then have mates to go out with and do other things that make their lives richer.”

In this short article, I retell the group's life history as related by Sally. I go on to analyse the group's achievements through the lens of critical disability studies.

Genesis as a Parents' Peer Support Group

Sally explains how the group got started.

“The background is, my son Alex was diagnosed with autism in 1994, when he was three. We went all the way to Kent – at the other end of the country – for assessment as there was nothing in Cumbria at that point. When I got back to Kendal with a diagnosis, I realized there was absolutely no peer support for parents. There was just nothing. I contacted social care services and health services to find out what was available, and they actually told me, ‘Well, there aren't enough people who would be interested to form a support group.’ I thought, right, okay, I'm going to set up a group myself anyway. I hired a room at a community centre in Kendal and made a flyer. This was before social media, so I went to put up a flyer at the town library. And when I was queuing to speak to the librarian, I noticed she had a National Autistic Society diary on her desk. So I thought, ‘That's very interesting.’ When it was my turn to speak, I introduced myself and said I was setting up a support group, and she said, ‘I have two autistic children myself, and I'd love to come to your group.’ And unbelievably, the lady behind me who was waiting in the queue said, ‘Oh my goodness. I've got an autistic son, and I'm in the queue to get advice about which books to read.’

So the universe somehow got us all together. And at the first meeting, eight people turned up, which was amazing considering it's a small town, and social services said nobody would be interested.”

“So we started out as a parents' support group on Tuesday mornings, and grandparents or anybody interested in talking to parents would come along. Initially we rented a room to meet at the community centre, but as room costs increased, we realised we either needed to fundraise or move somewhere free. And having witnessed so much effort going to fundraising we decided that we would just keep it informal, and we met at various cafes in Kendal. The group became quite popular and we began to work with social care services, just informally.”

Evolving to meet changing needs

The group evolved as autism awareness grew and austerity kicked in. After taking part in an inclusive training course for parents and people with disabilities, Parents in Policymaking, Sally and the group set up a charity (NPO), which enabled them to apply for funding. For a number of years, the group ran training for parents on person-centred planning, with financial backing from the county council. This turned out to be a wise priority, as when local authority funding was slashed by the new Conservative-led government in 2010, organisations that spent money on staff and premises disappeared. While the group could no longer fund training, they continued to meet informally.

Sally describes what triggered the group's reformulation as pub night.

“About seven years ago, out of the blue, the council employed somebody to run a group for parents of children with Aspergers, in the same community centre, at the same time as we used to meet. So then schools and health services all signposted parents to this new group. After working together with the council over so many years, I was actually quite upset, because it would have been nice to have a dialogue.”

“However, this was a catalyst for us to rethink our role. Times had changed. Alexander was about to leave school. And now a lot of parents couldn't meet on weekday mornings because they were working. So our group had a real brainstorming session about what was needed in Kendal, and from all the feedback we gathered, the thing that was missing was something for people on the high functioning end of the spectrum. These people fell through the cracks. They didn't get social care because they didn't have a learning disability, and they didn't get health care because they didn't have a physical disability. They fell nowhere, and they were really isolated. A lot of the parents were saying their young adults spent all their time in their bedrooms, they didn't have any friends, there were no connections. We decided to start meeting on a Thursday evening in a pub, and we marketed it for people with high-functioning autism. That was about six years ago. And it seems that decision was right, because we've developed into the group we are now. It's open to anybody, but it seems people from this part of the spectrum have found it most useful.”

Nurturing Relationships beyond the Autism Community

Sally sees one of her responsibilities as developing relations to ensure the group runs smoothly, and this means building awareness among people outside the autism community. For the Thursday night meeting, it entails maintaining positive relations with the bar manager and staff, so they welcome and support the group. One crucial job she does is to book the same table for the entire year, as many of the participants struggle with anxiety and feel more comfortable with a familiar discreet place. Together with the bar staff, the group has also checked around the pub for an alternative quiet table in case of a sudden need to shift.

At one stage however, a new manager took over the job, and group members felt he was unwelcoming to the point of being rude. Sally ended up contacting the manager's boss, who set up a time for the two to sit down over a cup of coffee.

“We just talked it through. I told him about the support group and autism. He told me his

expectations and why he appeared to be rude, and by the time we finished chatting he was very apologetic. Just by sitting together, having a cup of coffee and a conversation, we put it all to bed, and our relationship is really great now. He just hadn't understood. He knew some of us had autism, but he didn't know what that meant. He didn't understand that we have to be at the same place every time. He just needed enlightening about it all.”

Sally found the bar staff, a younger generation, more knowledgeable. But for them, too, she works to build relationships.

“We've never had a problem with bar staff. I think society in general has come a long way in autism awareness. They just understand because there's more on television and in the media. And also, when it comes to Christmas I make sure that I give them £50 for their Christmas party. And every week one of us will say thank you for being great bar staff, or buy them a drink or something. I think it's just showing we're appreciative.”

Linking Up with National Policy: Think Local Act Personal (TLAP) and the National Coproduction Advisory Board (NCAG)

In the course of supporting her own son locally in the early 2000s, Sally gradually got involved in collaborating with government to make public supports more effective for the people who use them, known in the UK as coproduction. This period was a progressive time for disabled people in the UK as well as globally, as it saw the adoption of the United Nations Convention on the Rights of People with Disabilities (CRPD) in 2006. The UK government shifted from a policy of providing group-based support for people with disabilities in segregated settings to providing person-centered (individually planned) supports within mainstream communities. This shift to supporting personal choice in adult social care was spelt out in the 2007 protocol agreement *Putting People First*, produced by a partnership of government, local authority, and voluntary organisations, and published by the Department of Health under the Labour government.

With jargon-busting clarity, Sally explains her involvement:

“In 2007 there was a concordat (Putting People First) that said the government wouldn't develop any policies or documents about disabled people and their carers without working with them, because it would make it more meaningful. An advert went out for anybody interested in being a part of a sort of reference group to work alongside the government in developing policies. I put my name forward, had an interview and became a member. It used to be called the User Reference Group, then became Transforming Adult Social Care Reference Group... And I started chairing the group because it was decided, look, this is a group of disabled people and carers, so it should be chaired by a disabled person or a carer, rather than a professional. It then went on to change its name to the National Co production Advisory Group.”

The NCAG works very closely with a national group of central government, local authority services and voluntary and private sector organisations, called Think Local Act Personal (TLAP), which developed directly from *Putting People First*. TLAP's mandate is to help organisations set up and implement community-based and person-centred approaches to adult social care.

Discussion

People on the high-functioning end of the autism spectrum may achieve academically, but struggle to communicate effectively to hold down a job or negotiate adult social roles. Although educational and support strategies abound, it is far from clear how best to support such individuals.

Critical autism studies (O'Dell et al. 2016; Bertilsdotter-Rosqvist 2019) encourages us to ask how understandings of autism are used in different contexts. Peer support groups for people with autism have often been used as a way to make people with autism “normal” by teaching them “normal” behaviours to pass as non-

autistic (Leaf et al. 2011). More recently, people with autism have set up autistic peer support groups on their own terms, to promote candid self-awareness while affirming autistic identity (Macleod 2010). Such groups may achieve their aims of peer support and autistic solidarity, and may also help participants address personal skill development.

However, at least in the UK context, autists still face discrimination by non-autistic people and some will require supports to manage daily life. The peer support group introduced here appears to be useful to participants on a number of fronts. On an emotional level, it affirms each individual's worth and supports autistic solidarity. Members have developed mutual friendships and intimate relations that go beyond the regular meeting times. On a practical level, it provides an informal source of information, and the friendships have motivated participants to develop independent living skills. On a social level, the parents stress the importance of raising autism awareness among the general public, to enable group members to access local resources such as the pub. Still more significant, although she has had limited success engaging with the county council, the founder has been proactive in linking up with national advocacy and coproduction to improve social policy and implementation for people with autism and learning disabilities.

The group also remains a place for the non-autistic parents to belong, finding friendships both with other parents and among the autistic “children.” At least for Sally, this cross-generational bonding is “symbiotic,” as she now is employed as a support worker for one of the young adult participants.

Conclusion

The South Lakeland Autism and Asperger's Support Group has created a supportive local space which mainly attracts people on the high-functioning end of the autism spectrum, who tend to be underserved by social care and health systems. Initiated by parents, it continues to evolve as members want, being proactive at identifying and filling in gaps in service provision.

As an observer, I felt that as the parents age, an upcoming issue will be raising the next generation of leaders, either among the group or by recruiting support staff. While it is beyond the scope of the current research, I would like to clarify how parents as a group and “children” as a group have used understandings of autism in their participation. For now, the group’s success points to the wide-ranging appeal and enduring joy of just coming together for a regular night at the pub.

Acknowledgements

I would like to thank Sally Percival and members of the South Lakes Autism and Asperger’s Group for welcoming me on Thursday nights. Cheers