

Delivering holistic low-level support to intellectually able autistic adults: lessons from an advocacy, information, and mentoring service
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Editorial comment

There are many intellectually able autistic adults who would like to have a better quality of life but who struggle to access advice and support from traditional services. This situation leads to emotional distress and poor outcomes for these individuals and their families and society generally. So services such as the Leeds AIM (Advocacy Information and Mentoring) service described in this paper have great potential in enhancing the lives of this group and in educating mainstream services on how advice and support might be adjusted to allow better access. In addition, creating good spaces for autistic adults offers opportunities for social contact and friendships with like-minded peers both within and outside the service.

Introduction

Autistic adults are at increased risk of experiencing poor mental and physical health (Howlin and Moss, 2012, Lake et al., 2014, Gotham et al., 2015), unemployment or under-employment (Baldwin and Costley, 2016, Lake et al., 2014, Gotham et al., 2015), social isolation (Tobin et al., 2014); and limited autonomy and independence (Renty and Roeyers, 2006, Howlin and Moss, 2012). These negative experiences not only affect their

quality of life but also incur significant costs to their families and society, generally.

The need to provide appropriate support for intellectually able autistic adults is increasingly recognised in the United Kingdom, as in other Western countries (i.e. Mental Health Commission of Canada, 2012, National Institute of Mental Health, 2016). Policy in the UK proposes to move services towards preventative work in the community with 'low-level support based around interpersonal networks and advice' (i.e. Department of Health, 2014, Department of Health, 2015). However, ongoing cuts to public funding raise questions about the implementation and effectiveness of this strategy.

Low-level support

Low-level support refers to a broad range of non-intensive, general support given to people in their everyday lives. It can be delivered in a variety of ways, by statutory health and care services, the voluntary and community sector (VCS) and through remote services (eg telephone, Internet) (Lorenc et al., 2016). Previous evaluations of autism 'one-stop-shops' in Scotland (Tait et al., 2013, National Centre for Autism Studies, 2006, National Centre for Autism Studies, 2007) and Leeds (Southby and Robinson, 2017) have shown the benefits that this type of low-level support can have for able autistic adults, their families, and service providers. Although many of life's difficulties persist, this low-level support helped adults to overcome barriers to obtain further support, leading to beneficial outcomes down the line.

Aim of the paper

The aim of this paper is to consider some of the key factors underpinning the perceived success of low-level interventions at Leeds AIM.

The service was established in January 2015 after a local needs analysis identified a gap in citywide provision for those with little or no funded support. It builds on previous projects in the city using volunteers to support adults with Aspergers. Leeds AIM was initially set up with six months funding from the Department of Health Autism Innovation Fund, following an autism citizen advocacy project that received a high amount

of referrals of autistic adults without a learning disability who were often in crisis. At the time of the study, Leeds AIM was funded by Leeds North CCG, Leeds South and East CCG, the Health and Social Care Volunteering Fund, and The Brelms Trust.

A project coordinator/manager has overall responsibility for the service. A part-time volunteer coordinator oversees the recruitment and training of volunteers, who themselves support at the drop-in hubs or act as mentors. A part-time hub facilitator supports the running of the hub services. A part-time information officer is responsible for producing written materials and managing the website. Two support workers are also funded by the Local Authority to staff the drop-in hubs. Adults with autism are involved in the service steering-group and as drop-in hub volunteers, peer-mentors, and delivering group sessions at the drop-in hubs.

The service consists of:

- ***two autism hubs***

These hold weekly drop-in sessions. One hub in the city-centre is open every Tuesday 1.30:pm-7:00pm and the other is in the south of the city is open every Thursday 2:00pm-7:00pm. These hubs provide access to a range of support and information, café areas, quiet areas, computer rooms, meeting rooms, and host external support services, (eg from the Citizens Advice Bureau and Department of Work and Pensions;). Attendance to the hubs does not require a formal autism diagnosis. During the evaluation period (January 2015-October 2016) over 200 people attending the drop-in hubs. More men attend the hubs than women.

- ***autism mentoring***

This pairs individual service-users with a specially trained volunteer for one-to-one support. - Mentors generally meet with the person once a fortnight to help identify goals and overcome barriers through providing information, and support with strategies. Mentoring matches vary in length but are expected to last up to 18 months. Service users need a

formal autism diagnosis in order to access the mentoring service. In the first year, 19 mentoring matches were made (15 males, 4 females).

- ***information and signposting***

This provides information in print and on the Leeds Autism Directory website, and via telephone and email correspondence. Service-users can also talk with members of staff at the hub.

Methods

Thirty interviews were conducted in total with able autistic adults (n=14), their family members (n=3), volunteer mentors (n=2), and professionals connected to the service (n=11). An invitation to be interviewed was emailed to all those on Leeds AIM's mailing list (including services users, professionals, and other stakeholders), asking those interested in taking part to contact the research team. A member of the research team also attended the city centre hub on four consecutive Tuesdays to meet those in attendance and invite them to take part in the project. Relevant professionals were identified by Leeds AIM manager and contacted by the research team.

Interviews were conducted in a way to suit the preferences of the participants and included face-to-face, email, and telephone interviews. Face-to-face and telephone interviews lasted between 12 and 58 minutes, the average being 22 minutes. Participants were asked about their experience of the Leeds AIM service, the outcomes they had achieved, and how the service could be improved. With permission from participants, interviews were audio recorded and transcribed.

Findings

Leeds AIM was described in overwhelmingly positive terms and was thought to lead to positive outcomes with regard to employability, education, volunteering, access to information and support, social isolation, health and wellbeing, managing day-to-day, communication skills, and autism awareness. This success was attributed to a number of overlapping and interconnected factors.

Value of the hubs as ‘one-stop-shops’

The multidimensional nature of the problems autistic adults might experience means it is advantageous for services to be grouped together and provided holistically. Leeds AIM was able to do this and ‘*provided a little bit of help for everything*’ (SU8). In addition to the information and signposting, having other services (eg Citizens Advice Bureau, Job Centre Plus) available within the drop-in hubs was very beneficial for service users. One adult said,

‘I did know there was a Citizens Advice Bureau (CAB) in town but I don’t like town. It’s very, very busy and the Citizen’s Advice Bureau in town - you’ve got to be there half an hour before it opens just to get seen, so it’s something I never did’ (SU10).

Autistic adults may struggle to access services in ‘mainstream’ settings. The availability of services within the drop-in hubs allowed service users to safely and confidently access services in a supported environment.

Value of Leeds AIM being autism specific and service-user led

Whilst much of the support and information provided by Leeds AIM might be available elsewhere, other settings were not viewed as favourably. Leeds AIM, as an autism specific service, co designed and co-led by autistic adults, was thought to better understand the experiences and needs of people with autism and their families. This was thought to encourage greater engagement and to lead to better outcomes.

An important factor in the successful delivery of the service was that autistic adults were recognised as experts by experience and involved in the design and operation of the service as volunteers (eg as mentors and steering group members) and in paid roles (eg delivering sessions). Service user involvement also had a transformative effect for some of the individuals involved. There was a pathway from service user to volunteer to employee (within the service or externally).

Autism-friendly environment

The physical environment of the drop-in hubs was praised by service-users as autism friendly. The drop-in hubs were described as quiet and peaceful; places where adults were able to ‘*chill out*’ (SU5) and ‘*get away from [negative] things*’ (SU1). Having a quiet room where service users

could relax as they wished (ie reading, playing computer games, talking) without any pressure to engage with others, was particularly appreciated.

However, there was some concern that as drop-in hubs became more popular, particularly in the city centre, they may become increasingly 'daunting' and 'overloading' spaces(SU14). Despite the best intentions of having a quiet room within which service users could relax, limited resources meant these spaces risked being taken over for other activities.

An accessible time and place

The times and locations of the services (the drop-in hubs and mentoring) were also praised as part of an 'autism friendly' environment. The drop-in hubs were held at a regular time each week, which supported service-users who liked a sense of routine. In addition, as the term drop-in suggests, service- users had no obligation to attend at particular times, which benefitted those who experienced anxiety around attending meetings, or who might struggle to arrive at a given time. It also allowed service-users to choose to use the hubs for informal socialising. The drop-in hubs remain open between 2:00pm and 7:00pm, which allows service-users to attend around other commitments such as work. However, the flexibility of the drop-in service was criticised by some who wanted to be able to book appointments or who had to wait to see staff who were busy with other people.

The location of the city centre service was praised as it was accessible for people using public transport but the hub in the south was not easy to access. Travel and transport links are very important for this group, few of whom have their own transport and many faced an additional recognised barrier in lack of confidence in travelling on public transport, particularly on unfamiliar routes.

Open to all and self-referral

Unlike many other autism services, Leeds AIM has no criteria for referral and access. It was therefore seen to be '*plugging a gap*' (SU13) for autistic adults who had limited access to other forms of support. That the service required '*no funding...and no booking*' (SU13) was seen as an important factor. As self-referrals were accepted, people with little or no funding, including those without an official' diagnosis of autism, were able to

access support. Moreover, the self-referral and open nature of the service shifted the responsibility to participate onto service-users, encouraging them to engage with the service. One service user said '*service users get out of it, what they put in*' (SU6). A downside of this approach, however, was that those most in need of help and support might be least likely to engage.

Person-centred, advocacy principles

A key barrier for autistic adults in accessing services is not being able to articulate their needs and wishes. A significant factor in the successful operation of Leeds AIM was thought to be their underlying advocacy principles. That is to say, service staff and volunteers support service-users to understand their needs and goals and communicate these more effectively in order to make decisions for themselves and to create their own goals. Leeds AIM use a 'person-centred' approach. By focusing on individuals' wants and needs, service-users were more satisfied with the process and outcomes achieved. However, where expectations and relationships are not managed effectively, this strength-based approach can lead to frustration and disengagement from service users.

Knowledgeable and caring staff

Service staff and volunteers were roundly praised by service users. One said, '*The people here make it work and their attitude*' (SU10).

Staff and volunteers were commended for their substantive knowledge about autism and autism services in the city and for their personal attributes. Staff were described as friendly, empathetic, understanding, patient, non-judgemental, and non-biased. The '*personal touch*' (SU5) made service-users feel more comfortable, building a trusting, working relationship. The consistency of staffing – being available every week at the drop-in hubs – also helped service-users feel comfortable with staff members/volunteers. This was thought to lead to service-users 'opening up' to accept support and engage with the service. Volunteers and mentors praised the quality of the training provided by Leeds AIM in preparing them for their roles.

The manager of Leeds AIM was praised, in particular, for her role in delivering the service. She was seen as key to coordinating the activities

within the drop-in hubs and was a knowledgeable and understanding intermediary for the adults, their families and service providers.

Mentoring and peer mentoring

Reflecting the importance of staff and volunteers, the mentoring element of the service was widely praised. A key factor was the mentors' experience and knowledge of autism and an understanding of the 'autistic experience'. Peer-mentors were praised as being relatable. The training provided to mentors was thought to give a good understanding of autism and a foundation for their work.

Collaborative working with other agencies

Collaborative working with other statutory and non-statutory organisations enabled service-users to readily access support at the drop-in hubs and facilitated effective signposting to external agencies. A key example of collaboration was with the adult social care mental health service in the local authority. This service provided the building space and two staff members for the drop-in hubs. Key collaborators were the Citizens Advice Bureau and Job Centre Plus who both provided weekly clinics at the drop-in hubs. Other agencies were supported to provide workshops and sessions. Collaborative working was thought to enhance and build up the skills of external partner organisations by increasing autism awareness and supporting them to engage effectively with this group. .

Discussion

The low-level support provided by Leeds AIM was found to lead to a number of positive outcomes for able autistic adults, their families, and services in the City (Southby and Robinson, 2017). The significance of Leeds AIM was in enabling adults to overcome many of the barriers to accessing appropriate support that they might otherwise face.

The physical environment of the drop-in hubs was thought to be 'autism friendly' compared to other services that can be daunting and uninviting for autistic adults. Being free-at-the-point-of-use and flexibility or access were significant for service users and their families with little or no other funded support, as cost can otherwise be a significant barrier to accessing services (Vogan et al., 2016). Moreover, having eligibility criteria based

on age or diagnosis was significant in the success of the drop-in hubs. As with the Scottish one-stop-shops, good strategic and operational management was a key asset in the success of the hubs (Tait et al., 2013).

Due to its strong advocacy focus, Leeds AIM represented the views of autistic adults at a strategic level on the autism partnership board and ran consultation sessions with outside agencies, such as housing, police and other services at the hubs. The steering group is autistic led. However, Leeds AIM did not involve representatives from social care, health, education, housing, police and other services on the service steering group as in Scotland (Tait et al., 2013). This did not appear to adversely affect service users perception of the service, although the effect on the outcomes achieved is unknown. It may be that involving agencies at a strategic level would have brought services together to develop stronger support networks with each other (Tait et al., 2013)

Concluding comments

Despite the areas of success reported for Leeds AIM, areas of concern exist and improvements can be made. More effective management of service-user expectations around communication, waiting times, and outcomes could prevent service users feeling dissatisfied with the service. Further collaborative working with other external organisations (eg housing, police and social care) may support service-users to achieve more positive outcomes. Further use of online media may enable Leeds AIM to further breakdown the barriers in accessing support reported in a number of studies (Benford, 2008, Davidson, 2008, Henderson et al., 2014, Kuo et al., 2014), although this should be seen as supplementary to the current face-to-face provision. Service-users would like to see the Leeds AIM service expanding to provide more services to a greater number of people across the city. However, challenges to any growth or change, aside from resources, is that the autism friendly approach might be compromised.

The issue of sustainability is an obvious and ongoing concern (Tait et al., 2013). The key to the success of Leeds AIM is that it is autistic led and tailored to the specific needs of the autistic adults who use the service. However, partly through its own success, Leeds AIM is coming under

increasing pressure with greater numbers visiting the drop-in hubs, and growing waiting lists for mentoring. This pressure is particularly acute as public funding is cut. Whilst the one-stop-shop model represents an effective and relatively inexpensive means of enabling autistic adults to access support, their ongoing ability to do so effectively within the context of austerity is unclear.

Leeds AIM update

Since the evaluation was completed in December 2016, the service has expanded to meet increasing demand. Additional funding has come from the local CCG and the Big Lottery. Leeds AIM have expanded to use the whole host building for the Tuesday drop-in hub. They also now run a second session in the city-centre on a Friday afternoon (3:30pm – 7:00pm) for booked appointments. The mentoring service is more closely linked to the hubs and supports service users to access wider volunteering opportunities. Additional groups have developed, with the women's group being the most well used.

The local authority autism reference group runs from the hubs, which increases the strategic reach of the service. More agencies run sessions at the drop in hubs, including Leeds Autism Diagnosis Service. Leeds AIM is now majority autistic staffed. An advocacy approach continues to be integral to the service.

References

- Criminal justice system and autism project. 2013/12//. British Psychological Society, 887-887.
- BALDWIN, S. & COSTLEY, D. 2016. The experiences and needs of female adults with high-functioning autism spectrum disorder. *Autism*, 20, 483-495.
- BENFORD, P. 2008. *The use of Internet-based communication by people with autism*. Electronic Thesis or Dissertation, University of Nottingham.
- DAVIDSON, J. 2008. Autistic culture online: virtual communication and cultural expression on the spectrum. *Social & Cultural Geography*, 9, 791-806.
- DEPARTMENT OF HEALTH 2014. *Think Autism: fulfilling and rewarding lives, the strategy for adults with autism in England: an update*, London, Department of Health.

- DEPARTMENT OF HEALTH 2015. *Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy*, London, Department of Health.
- GOTHAM, K., MARVIN, A. R., TAYLOR, J. L., WARREN, Z., ANDERSON, C. M., LAW, P. A., LAW, J. K. & LIPKIN, P. H. 2015. Characterizing the daily life, needs, and priorities of adults with autism spectrum disorder from Interactive Autism Network data. *Autism*, 19, 794-804.
- HENDERSON, V., DAVIDSON, J., HEMSWORTH, K. & EDWARDS, S. 2014. Hacking the master code: cyborg stories and the boundaries of autism. *Social & Cultural Geography*, 15, 504-524.
- HOWLIN, P. & MOSS, P. 2012. Adults with Autism Spectrum Disorders. *The Canadian Journal of Psychiatry*, 57, 275-283.
- KUO, M. H., ORSMOND, G. I., COSTER, W. J. & COHN, E. S. 2014. Media use among adolescents with autism spectrum disorder. *Autism: The International Journal of Research & Practice*, 18, 914-923.
- LAKE, J. K., PERRY, A. & LUNSKY, Y. 2014. Mental Health Services for Individuals with High Functioning Autism Spectrum Disorder. *Autism Research & Treatment*, 1-9.
- LORENC, T., RODGERS, M., REES, R., WRIGHT, K., MELTON, H. & SOWDEN, A. 2016. *Preventative co-ordinated low-level support for adults with high-functioning autism*, London, Evidence for Policy and Practice Information and Co-ordinating Centre.
- MENTAL HEALTH COMMISSION OF CANADA 2012. *Changing Directions, Changing Lives: The Mental Health Strategy for Canada*, Calgary, Mental Health Commission Canada.
- NATIONAL CENTRE FOR AUTISM STUDIES 2006. Final Evaluation of the Autism Resource Centre (ARC) in Glasgow. Strathclyde.
- NATIONAL CENTRE FOR AUTISM STUDIES 2007. Evaluation of 'No. 6': the One-stop-shop for adults with Asperger's Syndrome and High Functioning Autism, in Edinburgh and the Lothians. Strathclyde.
- NATIONAL INSTITUTE OF MENTAL HEALTH. 2016. *Autism Spectrum Disorder* [Online]. Available:

<https://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd/index.shtml> [Accessed December 2016].

- RENTY, J. O. & ROEYERS, H. 2006. Quality of life in high-functioning adults with autism spectrum disorder: The predictive value of disability and support characteristics. *Autism*, 10, 511-524.
- SOUTHBY, K. & ROBINSON, O. 2017. Information, Advocacy and Signposting as a Low-Level Support for Adults with High-Functioning Autism Spectrum Disorder: An Example from the UK. *Journal Of Autism And Developmental Disorders*, 48, 511-519.
- TAIT, C., IBBOTSON, R., MACBEAN, R. & LENNON, P. 2013. The 'Autism One Stop Shop': a developing model in Scotland. *GAP*, 14, 20-27.
- TOBIN, M. C., DRAGER, K. D. R. & RICHARDSON, L. F. 2014. A systematic review of social participation for adults with autism spectrum disorders: Support, social functioning, and quality of life. *Research in Autism Spectrum Disorders*, 8, 214-229.
- VOGAN, V., LAKE, J. K., TINT, A., WEISS, J. A. & LUNSKY, Y. 2016. Tracking health care service use and the experiences of adults with autism spectrum disorder without intellectual disability: A longitudinal study of service rates, barriers and satisfaction. *Disability and Health Journal*.