

Developing a user-informed training package for a mentoring programme for people on the autism spectrum

Tara Sims, Damian Milton, Nicola Martin and Gemma Dawkins
London South Bank University.

Background

The National Audit Office's (2009) report 'Supporting People with Autism through Adulthood' highlighted the dearth of services for adults on the autism spectrum, and the negative impact this has on this group. It reported that only 12% of adults on the autism spectrum were in full-time paid employment and that 70% had additional mental health problems.

At the 2007 forum 'Successful Futures for Adults with Autism', people on the autism spectrum were asked to share their thoughts on existing models of support and how they would like support to be. The participants highlighted difficulties they experienced with navigating social life. There was a common feeling that existing models of support for adults on the autism spectrum, such as befriending, were not helpful. Many said that they would benefit from time-limited, goal-oriented, specialised mentoring. Participants identified they would benefit from support with managing practical and financial affairs; accessing education/training opportunities; securing and maintaining employment; and maintaining good physical and mental health. As a result of this, the Research Autism Mentoring Project was instigated with the aim of developing a user-informed and evidence-based mentoring service for adults on the autism spectrum.

Review of existing guidance

Much guidance that has been written for preparing and supporting people on the autism spectrum in post-compulsory education has been done so from a clinician's perspective. This guidance provides suggestions for interventions to address academic modifications, independent living and social skills, vocational goals, and mental health supports in order to improve the quality of life of such students (VanBergeijk et al. 2008, NAS, 2011). Strategies suggested in this guidance include role playing, generalising, and teaching people on the spectrum to recognise their own emotions through explicit instruction.

These strategies have been criticised by a number of autistic scholars and activists (Milton, 2012, 2014). Role playing, for example, although beneficial to some people, can cause high stress levels in others. This may be due to difficulties with generalising and the artificial nature of role play. As a result, people may over-generalise from learnt 'rules' and 'scripts',

leaving them unprepared for unanticipated events. Additionally, explicit instructions regarding social phenomena that are learnt implicitly can lead to what is then perceived as 'rigidity' in autistic actions within social settings. Despite these criticisms, the guidance does suggest some more helpful strategies, including having smaller setting and class sizes and focusing on and utilising a person's strengths and interests rather than their difficulties. Issues such as this highlight the need to understand the personal 'constructions', learning styles and perceptions of the autistic people one is working with or trying to mentor in such settings.

Review of the evidence-base

A literature search of research on mentoring for people on the autism spectrum in employment and post-compulsory education yielded very few results, highlighting the dearth of research conducted in this area. One study identified was a systematic review, conducted by Gelbar et al. (2014), of research studies describing the experience and support schemes made available for people on the autism spectrum attending College or University. Gelbar et al.'s (2014) systematic review considered twenty articles, which referred to only 69 participants in total. Furthermore, the majority of the studies were individual case study reports, demonstrating the real scarcity of research in the area. Gelbar et al. (2014) found that the majority of the studies looking into experiences of post-compulsory education included accounts of isolation and loneliness, and problematic mental health, highlighting the need for better support.

The Mentoring Project

In light of the limited evidence-base and the criticisms of existing guidance, a two-year pilot study was funded by Research Autism to establish a mentoring scheme, designed with input from people on the autism spectrum and their families and supporters. The impact of the scheme in improving the wellbeing of adults on the spectrum will be rigorously examined. The Project was granted ethical approval by London South Bank University Research Ethics Committee (approval number UREC 1469) in March 2015.

Methods

A minimum of 12 mentors will receive specialist training on mentoring someone on the autism spectrum and be matched with mentees. Mentees and mentors will collaboratively come up with goals for mentoring and the mentoring itself will take place for six months. Various measures will be used to assess its effectiveness and gain the views of mentees and mentors on their experiences of participating in the programme: the Personal Wellbeing

Index (International Wellbeing Group 2013), qualitative interviews, the Salmon Line (Salmon 1995) and records from the mentoring sessions.

Understanding the well-being of adults on the autism spectrum

Current measures of wellbeing used in the context of autism have been developed with a non-autistic population and, hence, may not adequately reflect an autistic perspective. Therefore, this area of research has been gaining increasing attention. A number of studies have shown the potential of utilising Personal Construct Theory (PCT, Kelly 1955) with autistic populations however for gaining a clearer insight into the perspectives of autistic participants. Within PCT, people were initially regarded as lay 'scientists', developing theories about the world and testing them out in real life situations. Although this idea can be critiqued, as people are often not conscious of the decisions they make and the meanings they form, as Moran (2006) suggests, this way of meaning-making may be more aligned with some autistic sensibilities. By focussing on how an individual construes the world, idiosyncratic constructions are anticipated and better understood, helping practitioners to engage with the autistic people that they work with. In the current project, the Salmon Line technique (Salmon 1995), which was developed out of PCT, has been adapted for mentors and mentees to use to analyse progression towards goal achievement from the subjective viewpoint of the participants.

Developing the training

We have developed a one day training programme for potential mentors, which is delivered by a range of people from the project team and the advisory board (both people on the autism spectrum and people experienced in working with people on the spectrum. People on the autism spectrum were involved throughout in developing, refining and delivering this training through participating in an advisory board to identify the key areas to address; attending a pilot session of the training to give feedback on the day and make changes and improvements; and delivering training sessions.

The training includes sessions on autism in an historical and social context; psychological theories of autism; the lived experience of autistic people (including sensory issues and gender identity); mentoring techniques for people on the autism spectrum (including an introduction to the use of personal construct theory); the SPELL framework (The National Autistic Society); and practical information about the project's procedures and paperwork. The training includes a mix of traditional lectures and group activities, using case studies as triggers for small group discussions to encourage problem-solving of various hypothetical scenarios.

Evaluating the training

In addition to carrying out a pilot training session with members of the advisory board, extensive feedback has been collected from participants following each of the training sessions. Feedback from the training sessions has, in the majority, been very positive. The most common criticism received was that one day is not a sufficient length of time for the breadth of information covered: participants suggested they would benefit from more time to explore all of the issues involved. An additional consideration was the difficulty in tailoring training to the individuals attending the session: some participants had much experience in the field of autism or mentoring, whilst others had not, making it difficult to meet the learning needs of all participants in a single one-day session.

The future of the project

The project has developed a specialist one-day training course for mentors of people on the autism spectrum. People on the autism spectrum have been involved in developing, refining and delivering this training. To date, more than 40 people have received this specialist training and many have gone on to join the pool of mentors for the project. Mentors have been matched to mentees and are midway through their six-month mentoring relationships. At the end of the six-month mentoring period, we will have both quantitative and qualitative data with which to evaluate the effectiveness of the programme. Concurrent to the six-month mentoring period, the training materials are being further developed and modified (by the research team and the advisory board) to create a training materials package that can be delivered in a variety of contexts and settings.

References

National Audit Office (2009) *Supporting People with Autism through Adulthood*. Retrieved 14/10/14; available at: <http://www.nao.org.uk/wp-content/uploads/2009/06/0809556.pdf>

VanBergeijk E, Klin A and Volkmar F (2008) Supporting More Able Students on the Autism Spectrum: College and Beyond. *Journal of Autism and Developmental Disorders*, 38: 1359-1370.

National Autistic Society (2011) *Supporting students on the autism spectrum: student mentor guidelines*. London: The National Autistic Society.

Milton D (2012) On the Ontological Status of Autism: the 'Double Empathy Problem'. *Disability and Society*, 27(6): 883-887.

Milton D (2014) Autistic expertise: a critical reflection on the production of knowledge in autism studies. *Autism: The International Journal of Research and Practice (special edition 'Autism and Society')*, Onlinefirst, 17/03/14.

Gelbar N, Smith I and Reichow B (2014) Systematic Review of Articles Describing Experience and Supports of Individuals with Autism Enrolled in College and University Programs. *Journal of Autism and Developmental Disorders*. Published online: 11/05/14.

Salmon P (1995) *Psychology in the classroom - Reconstructing teachers and learners*. London: Cassell.

Kelly GA (1955) *The Psychology of Personal Constructs*. New York: Norton.

Moran H (2006) A very personal assessment: using personal construct psychology assessment technique (drawing the ideal self) with young people with ASD to explore the child's view of the self. *Good Autism Practice*, 7(2): 78-86.

National Autistic Society (Epub) *SPELL*. London: National Autistic Society.