

The development and evaluation of a mentor training program for those working with autistic adults

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London South Bank University (LSBU) has recently set up the Participatory Autism Research Collective (PARC) with a view to ensuring that autistic expertise influences autism research. Many of the steering and advisory group members for this project also contribute to PARC and we thank these autistic experts for their valuable contribution to this project. The research reported in this paper received funding from Research Autism.

Editorial comment

This paper evaluates the training developed for potential mentors wanting to work with autistic adults to enable them to work towards their chosen goals. It then gives some initial findings of how the mentoring worked in practice. Research Autism provided the funding to offer a one day training event free to adults who expressed a wish to work as a mentor. Fifty people were trained and 45 of these completed a feedback form. This provided excellent information on the content and delivery. The most highly rated aspect of the training was the fact the much of the content was developed and delivered by autistic adults. The most often cited way to enhance the training would to extend this to two days as a great deal was packed into the day. Not all those who attended the training went on to act as mentors but it was felt they would have gained from receiving the training. It was felt that short-term, goal oriented mentoring was likely to be the most effective. There is little data presented on the goals the mentors worked on and with what degree of success as that is the subject of future papers. Instead the focus was on the training offered. It came to light that some of the mentors who did start to work with autistic adults were not reliable and so future training will stress the importance of this. A key point throughout the paper is the need to involve autistic individuals in training and interventions designed for autistic people. Such work is slowly developing and becoming more common and this paper adds to the literature on this.

Introduction

Practical support for adults on the autism spectrum is limited and patchy and research into what effective support might look like is sparse. The nuanced needs of autistic adults within educational and work settings are therefore poorly understood and inconsistently addressed. At a forum held by Research Autism in 2007 entitled '*Successful Futures for Adults with Autism*', participants highlighted difficulties with navigating social life, including: managing

practical and financial affairs, accessing education and training opportunities, securing and maintaining employment, and maintaining good physical and mental health. Existing models of support, which often involve being part of a large group, were described as unhelpful and stressful by participants, many of whom favoured one-to-one, time-limited, goal-oriented, specialised input based on a personal life coach or mentor model, at least initially, with the possibility of broadening arrangements over time. Participants said they would like to use the allowances they received for personal support to pay for such services, but few had access to anything like this in their locality.

The findings of ‘Successful Futures...’ led Research Autism to fund The Cygnet Project, a two-year pilot study to establish and evaluate a mentoring scheme, designed with significant input from autistic people and their families. The evaluation had two main foci: the effectiveness of the intervention in improving the well-being of the participants and helping them to progress toward their own stated goals, and the usefulness of the mentor training. The remit of the project included the production of a one-day training course for would-be mentors of autistic adults, underpinned by desk-based research and informed by advice from the project advisory and steering groups which were made up of autistic adults and allies. Production was informed by ascertaining (from published information and discussion with the steering and advisory groups) the sort of information and activities likely to be most effective for meeting the training needs of would-be mentors of autistic adults. Evaluative activities included asking would-be mentors which aspects of their training programme they most appreciated and what might they like to change.

The majority of work that has previously been undertaken in the area of mentoring autistic people has been situated within a medical / behavioural model and also designed without significant autistic input (Griffith et al. 2012; Curtin et al. 2015; Arnes et al. 2015), and few have been subject to rigorous evaluation (Gelbar et al. 2013). This has led to the focus of such programs being primarily aimed at concerns driven by the non-autistic population, such as the learning of ‘social skills’ (Milton, 2016) and often normative, remedial and normalising in outlook. Current mentoring practice for autistic people in the UK is often not supported by adequate training and supervision, yet recent work by Hamilton et al. (2016) suggest such training is essential for successful mentoring practice.

This paper concentrates on the area of the research which relates to the development and evaluation of mentor training. The implementation of the mentoring scheme is discussed and initial findings presented. Subsequent publications will focus on the mentoring scheme and provide details of the mentor training, as background.

Methodology

Principles

Ethical approval for the project was secured from London South Bank University Ethics Committee. Operating from an ‘emancipatory research’ standpoint, user involvement was central to the design of this project and its activities. The mentoring scheme and training

was designed by people on the autism spectrum, including a member of the research team and members of an advisory panel.

Traditional research in the social sciences has arguably perpetuated unequal power relationships experienced by historically marginalised groups of people who are more used to research being done 'to' rather than 'with' them (Barnes & Sheldon 2007). The 'emancipatory' research paradigm purports that research should be of use to participants (rather than primarily for researchers) and participants should experience involvement with and control over the research agenda and process (Barnes & Sheldon 2007).

Introducing the programme and recruiting potential mentors

Potential mentors and mentees aged 18 years and over, were invited to take part through poster advertising at Universities and Further Education Colleges, and internet forums operated by: Research Autism (RA), The National Autistic Society (NAS), The National Association of Disability Practitioners (NADP) and The Disability Equality Research Network (DERN). Respondents to the recruitment advert received an introductory letter, participant information sheet and expression of interest form. Consent was sought at the beginning of this process and checked at intervals throughout the mentoring program.

Parameters for the role of the mentor were clearly defined in the training and in guidance documents for mentors and mentees. Content included information on mentoring skills, risk assessment and safeguarding, and positive ways of working with autistic adults informed by an 'insider perspective'. Following training, all participants still interested in becoming mentors undertook DBS checks (Disclosure and Barring Service) and an interview process before being admitted to the mentor pool. Attendees were made aware that the training would be evaluated through feedback forms which included both qualitative (open) and quantitative (closed) questions. Further evidence on the usefulness of the training was reviewed after delivery of the mentoring program through interviews with participants.

The training was initially piloted with the advisory group and adapted based on their feedback which suggested that personal references in the training material needed to be removed in order to standardise the information and more time for discussion and activities was required. The training was revisited and amended based on the evaluations of each of four sessions.

Content of the mentor training programme

The mentor training was constrained to one day broken up into 30 minute time slots as follows:

- An introduction to the project, aims of the training day, and introduction to mentoring.
- Autism in an historical and social context.
- A different way of thinking.
- Sensory perceptions and autism.
- Interaction and communication.
- Stress and anxiety.

- Autism and gender.
- The SPELL framework. (NAS, 2016)
- Boundaries, recording risks and safeguarding.
- The Personal Well-being Index (PWI), goal-setting and Personal Construct Theory (PCT).
- Concluding guidance.

The introductory session sought to settle participants into the expectations of the day and the project and introduce current mentoring theory and practice. Attendees were invited to reflect on the differences between mentoring and other support roles such as counselling, advocacy, befriending, and coaching. Input on historical and social context explored the origins of contemporary notions of autism and introduced models of disability and the framing of the project within a social model, emancipatory, and person-centred approach. Sections following related to: theories of autism and aspects of the autistic experience, and 'a different way of thinking' which introduced executive functioning theory, weak central coherence, and monotropism, as well as relevant criticisms of these theories. Interactive activities and case study examples were employed to help situate the theories in mentoring practice. Autism and gender was covered by an autistic woman who had been part of Research Autism's *Autism in Pink* project (2016).

The day concludes with input on framing the ethos of the project, reviewing role boundaries, advising on safeguarding issues, and covering the data collection requirements and supervision arrangements. This included an introduction to the NAS SPELL framework (NAS, 2016). SPELL concentrates on the needs of autistic people in terms of: Structure, Positive approaches, (building) Empathy, (employing) Low-arousal (techniques), and (building) Links (between the autistic person and significant others in their life). The REAL model was also introduced (Hastwell et al 2013). REAL emphasises the requirement for Reliability, Empathy, Anticipation and Logic in interactions with autistic people. Reliability was emphasised in training and this is commented upon further in the evaluation.

Following training, participants were asked to rate the experience on Likert scales (Jamieson 2004), in the following categories, from strong agreement to strong disagreement:

- A good balance of the information presented.
- Relevance and usefulness.
- Organisation.
- Usefulness of materials.
- Helpful to their mentor role.
- Subject knowledge of trainers.
- Meeting of expectations.
- Sufficiency of time.
- Room and facilities.

Participants were also asked a number of qualitative questions regarding: what they liked most about the project, what could be improved in the training, the likely impact on their practice, if anything should be added or removed from the training, and whether they felt that they needed additional input about understanding autism.

Evaluation of the mentor training

The evaluative tools used to capture feedback included a 5 point Likert scale allowing responses ranging from strongly agree to strongly disagree, and space for open-ended comments. *Table 1* gives the findings from the 5 point scale which are summarised across the four sessions. Additional comments are then discussed and illustrative examples are provided to add further clarity. All responses are carefully anonymised.

Over 50 individuals engaged with the mentor training over four full day sessions and the vast majority of evaluative comments were extremely positive, as were the Likert scores. Attendees were enthusiastic about the knowledge of the trainers delivering the programme, the organisation and flow of the sessions and the usefulness of the materials. The final training day scored highest of the four, probably reflecting the small changes made during the process, in response to feedback, and the trainers becoming more acquainted with the materials and timings. The benefit of having training designed and delivered with significant input from autistic people was consistently highlighted and has been adopted as an underpinning principle for all future training associated with the Cygnet project.

Table 1: Feedback from all four training days (average score on scale between 1 and 5 from strongly disagree to strongly agree):

Question	T1	T2	T3	T4
Good balance	4.2	3.9	3.8	4.6
Relevance/useful	4.6	4.2	4.5	4.9
Organised/easy to follow	4.6	4	4.5	4.6
Materials useful	4.7	4.4	4.3	4.8
Help in role as mentor	4.4	4	4.3	4.8
Trainers knowledgeable	4.8	4.8	4.8	5
Met expectations	4.2	4	4.3	4.5
Right length	4.4	3.6	4.3	4.5
Room/facilities	3.4	4.4	4	4.8

Exhausted attendees gave a clear message, especially during the second and third training days that the trainers had packed too much in to a single day. The researchers were constrained by the project brief and welcomed feedback which supported their view that more time was needed. The only negative comments came from two participants, one of whom was not really clear about the project remit and another who was an experienced mentor and understood SPELL already. Of the others who attended and offered feedback, the vast majority of responses were, as noted previously, very positive and encouraging.

Open ended comments about what attendees liked most about the training were analysed thematically. Broad themes are presented here, in order (highest first), according to the number of mentions throughout the four training sessions:

Speakers being on the autism spectrum

The balance, variety and structure of the content

Activities and discussions regarding strategies

Straightforward and informative materials

The talk on autism and gender being included

Networking and learning from others

Focus on more effective relationships

Less deficit-driven and mention of rarely covered issues (such as 'shutdowns')

The social model and person-centred account given to frame the project was also well received by attendees who were very clear that the best aspect of the training was that it was delivered by people with personal experience of autism.

"Valuable to have personal experiences and interpretations of the autism spectrum." (Participant from Training Day 2).

"Input from trainers with personal experience of autism." (Participant from Training Day 3).

The balance, variety and structure of the content, interactive activities of the training program and input on gender were also highly rated. One person felt that the differences between mentoring autistic and 'NT people' should have been addressed.

The second open question asked what could be improved about the training. The main themes in response to this question were:

More interactive activities or videos of mentoring in practice

Perhaps delivered over two days / too much information in time available

More information and advice on mentoring in practice and practical strategies

Environmental factors about the venue

Participants not wanting to change anything about the training

The pace of the training – for some too slow, others too fast

These responses indicate that the training was generally well received but would have benefitted from being delivered over two days to allow for more time for interactive activities and discussion of practical strategies.

The third open-ended question asked what impact the training would have on the practice of participants. The following main themes (in order according to numbers of responses) emerged:

Increasing understanding in person-centred approaches

Use of Personal Construct Theory (PCT) and the Salmon line

Providing structure and practical strategies

Feeling empowered as practitioners

Two of the 45 people said it would have little impact on practice

It is clear from these responses that the person-centred ethos coupled with the practical strategies and materials offered were seen as useful, particularly the use of the Salmon line (as developed from Personal Construct Theory (Salmon, 2003) and explained later).

“Shall incorporate the Salmon line – thank you.” (Participant from Training Day 2).

“PCT and the Salmon line – a useful visual support.” (Participant from Training Day 4).

When asked if attendees would change, add or remove anything from the training program, the following themes were identified:

Not changing anything

More on mentoring case studies and examples

More exercises and activities

Some slides could be delivered as a handout

Less on autism history

Creating videos of those who have experienced mentoring

By far the most common response to this question was that the content should not be changed but could be delivered over two days to allow more time with interactive activities and practical examples.

Lastly, when asked what additional training might be required, the most common themes were:

Additional training would be always helpful

A meeting once/twice a year to refresh knowledge

Videos of good / bad mentoring sessions

Looking into overlaps with mental health

Navigating forms and bureaucracy

Not needed (one respondent)

The suggestion of meeting again to refresh knowledge directly influenced the structure of the main mentoring program.

The mentoring program: matching mentors to mentees (autistic adults)

The full mentoring project looked to study the impact of mentoring on the well-being of 12 adults on the autism spectrum. Initially, an age range of 18 to 24 years was identified for mentees but the upper age limit was dropped because the team received enquiries from autistic people of 25 and over. Matching of mentor / mentee pairs was guided by the mentees' goals for mentoring, which they identified on their expression of interest form.

Some mentees received their mentoring within the context of a package of funded support in College or University, or through an Access to Work grant from the Department of Work and Pensions. Supervision was generally not built coherently into these roles. These autistic mentees were included in the current project, provided their mentors had received mentor training within the project. Other mentors were volunteers with experience of working with autistic adults. Mentors, whether paid or voluntary, had in the main received little training or ongoing supervision.

Various mentoring arrangements were implemented, including face-to-face and email based interactions depending on the preferences of the mentees. The researchers were cautious about ensuring safe practices such as meeting in public places, something which was emphasised clearly in mentor training. Each mentee received one hour of mentoring per week over a six month period. This time frame was chosen because of the conclusions of the Research Autism consultation held in 2007, that short-term, goal-orientated mentoring was likely to be more effective than a long-term 'befriending' style of relationship.

The Salmon Line (2003), a linear 1-10 scale, was used as a means of recording each goal. Mentees were required to work with their mentor to identify their end goal (eg to get a job) and to mark how far they were along the scale. This exercise formed the basis of discussions about actions the mentee might take to get them further along the Salmon Line and nearer to their end goal. All mentors and mentees were able to contact the research team during the programme in case of any issues they felt unable to resolve within their mentoring sessions. A peer support session was also available three months into the programme. Supervision arrangements for mentors were made explicit in training.

Initial findings from the evaluation of how the mentoring worked in practice

The findings from the mentoring programme have been very encouraging, with every mentee that completed the full six-months showing increases in well-being, substantial progress toward their self-selected goals and enthusiasm for the project. The use of the Salmon Line (Salmon, 2003) was referenced by some but not all mentors and mentees found this particularly useful. Some mentors reported finding it difficult to facilitate the initial setting of goals and some mentees struggled with this aspect of the program at first. This is something that requires further investigation.

During the mentoring program it was found that, disappointingly, the reliability of mentors was variable. Whilst the vast majority were reliable, when mentors were unreliable this clearly impacted negatively on the quality of the mentoring relationship. Although consistency and reliability were strongly emphasised in the mentoring training, possibly this needed added emphasis. The REAL acronym (Hastwell et al., 2013) was used to emphasise reliability(ie mentors needed to be Reliable, to Anticipate potential difficulties, to Empathise

with the mentee and to communicate Logically). This was sadly not as powerful and effective as anticipated.

Supervision by the project team was valued by mentors and thought to be crucial to the success of the project. Rarely was supervision found by the researchers to be a feature of mentoring schemes and this is concerning.

Concluding comments

The literature review for this research highlighted that current practices are not supported by a strong evidence base, and that improvements to training, supervision and the Continued Professional Development (CPD) of mentors working with autistic people is needed (Hamilton et al. 2016). The positive findings from this research would suggest that a larger scale project is required to build upon the model with the view of operationalising a mentor scheme that includes the significant components so far identified and strengthens those which need attention.

Training was very well received by the vast majority of participants. Those who went on to become mentors found the advice and materials offered of practical use. A great deal of useful information was packed into one day and feedback was clear that two days would allow more time to 'take it all in' and explore more practical examples and strategies. Some attendees suggested they would have liked video clips of mentoring in progress. The authentic voice of autistic people delivering the content was received extremely favourably and having a variety of autistic speakers was also highly valued. Autistic input in the design and delivery of the training significantly affected the content as well as allowing for nuanced explanations, examples and discussion. Trainers being knowledgeable, consistently scored highest in all of sessions. A key recommendation of this project is that autistic voices should permeate autism-focused mentor training. This project has given further evidence that such training can have added impact by being led by the concerns of autistic people, and following a person-centred and participant-led model.

Feedback from attendees of the mentoring training, alongside the findings from the full mentoring project, have both been very encouraging. Whilst aspects of the training have been highlighted for improvement (eg more emphasis on reliability and consistency, and the setting of goals), by far the most significant suggested improvement was expanding to a two-day model. The first day could concentrate on familiarising participants with the project and core aspects of autism, whilst the second could concentrate on mentoring practice using what had been learnt on the first day. Whilst it would have been of great benefit to have produced resources such as video footage of mentoring and case studies, this was beyond the remit and budget (as was two days of training). Such activities in future could enhance the mentoring training.

The training events were perhaps attractive to participants as they were offered for free, with many not applying to become part of the wider mentoring project. However, their participation in evaluation was helpful and the experience will have been useful to their practice and future interactions with autistic people.

An expanded research program could explore ways in which the project could realise its emancipatory aim of ultimately producing an intervention informed by, and practically useful to, autistic people. The project has already translated into CPD which is nationally accredited by the CPD Standards Office (when delivered by named speakers from the original team). As a matter of sustainability, consideration needs to be given to ways in which content could be delivered by other people without losing the qualities discussed here. CPD accreditation has been identified as a marker of quality and this route merits consideration. Further funding would be needed to extend the project, including developing the training into a two-day model. Trainers could be identified and trained, and then evaluation of the model undertaken on a wider scale.

Many potential benefits have been identified to time-limited and goal-oriented mentoring founded upon an ethos, training, and supervision model with significant input from autistic people. There has been a lack of rigorous evidence to base current mentoring practice with autistic adults upon, and much of the current evidence has been based on normative / deficit models with little autistic participation into the design and delivery of training programs. To offer mentoring to autistic people without a formalised and accredited training process and supervision structure is potentially damaging. Specific training in autism, let alone incorporating a social model perspective, person-centred approaches and insider viewpoints, does not seem to be currently required for practitioners to work as mentors with autistic adults in most settings, nor are there essential safeguards for both mentees and mentors. Mentoring delivered via the Disabled Student Allowance in the university sector is recently an exception requiring mentors to have undertaken approved CPD and the CPD accreditation associated with this project is fit for purpose.

The support needs of autistic adults can be very varied and idiosyncratic, but could include anything from managing finances and practical everyday living, to accessing education, training and employment. The needs of autistic adults are often unrecognised however, particularly when one takes into account the mutual incomprehension that ensues from the double empathy problem (Milton, 2012; 2014; Chown, 2014). Autistic adults have reported how current models of support have not met their needs, whilst mentoring can help with their progression and meeting goals. This project has shown that the input of well-qualified autistic people in the design and delivery of training can significantly enhance the experience and understanding gained by participants, a finding which has ramifications beyond that of mentoring practice.

Further papers currently under development will focus specifically on the implementation and evaluation of the mentoring scheme itself from the perspectives of value to mentors and mentees participating in the pilot. The findings of the pilot study are being used to refine all aspects of the mentoring scheme including training and delivery with a view to creating a sound platform for the extension of evidence-based approaches to mentoring with autistic adults informed by the expertise of autistic adults.

References

Autism in Pink (2016) [online]: <http://autisminpink.net/>, [Accessed 16/01/17].

- Arnes, M., McMorris, C., Alli, L., & Bebko, J. (2015) Overview and evaluation of a mentoring program for University students with ASD. *Focus on Autism and Other Developmental Disabilities*, focus.sagepub.com.
- Barnes, C. & Sheldon, A. (2007) 'Emancipatory' Disability Research and Special Educational Needs. In: L. Florian (ed.) *Handbook of Special Educational Needs*. London, UK: Sage.
- British Educational Research Association (2011) *Ethical Guidelines for Educational Research*.
- Chown, N. (2014) more on the ontological status of autism and the double empathy. *Disability and Society*, Vol. 29(10): 1672-1676.
- Curtin, C., Humphrey, K., Vronsky, K., Mattern, K., Nicastro, S. and Perrin, E. (2015) Expanding horizons: a pilot mentoring program linking college/graduate students and teens with ASD. *Clinical Pediatrics*, cpj.sagepub.com.
- Gelbar, N. Smith, I. & 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.
- Griffith, G., Totsika, V., Nash, S. & Hastings, R. (2012) 'I just don't fit anywhere': support experiences and future support needs of individuals with Asperger syndrome in middle adulthood. *Autism: International Journal of Research and Practice*, Vol. 16(5): 532-546.
- Hamilton, J., Stevens, G. & Girdler, S. (2016) Becoming a mentor: the impact of training and the experience of mentoring University students on the autism spectrum, *PLOS-ONE* [online], <http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0153204> [Accessed: 31/07/16].
- Hastwell, J., Harding, J., Martin, N., and Baron-Cohen, S. (2013) *Asperger Syndrome Student Project, 2009-12: Final Project Report, June 2013*. Cambridge: Disability Resource Centre, University of Cambridge.
- International Wellbeing Group (2006) *Personal Wellbeing Index*. Melbourne: Australian Centre on Quality of Life, Deakin University.
- Jamieson, S., 2004. Likert scales: how to (ab) use them. *Medical education*, 38(12), pp.1217-1218.
- Milton, D. (2012) On the Ontological Status of Autism: the 'Double Empathy Problem'. *Disability and Society*. Vol. 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.
- Milton, D. (2016) *Educational discourse and the autistic student: a study using Q-sort methodology [doctoral thesis]*. Birmingham: University of Birmingham.

National Autistic Society (2016) *SPELL* [online]:
<http://www.autism.org.uk/about/strategies/spell.aspx>, [Accessed: 31/07/16].

Salmon, P. (2003) *A Psychology for Teachers*. In F. Fransella (Ed) *International Handbook of Personal Construct Psychology*, Chichester: Wiley.

Shah, A. and Frith, U. (1983) An islet of ability in autistic children: a research note. *Journal of Child Psychology and Psychiatry*. Vol. 24, pp. 613-620.