

Executive Summary: Research Autism Cygnet Mentoring Project

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Background

The National Audit Office's (NAO, 2009) report *Supporting People with Autism through Adulthood* highlighted the dearth of services for adults on the autism spectrum. Negative impacts identified included the fact that only 12% of respondents of the NAO survey were in full-time paid employment; and a shocking 70% identified mental health problems. These figures are also supported elsewhere (NAS 2014).

The support requirements of intellectually able adults with autism can be just as nuanced as those for people who have significant learning difficulties/disabilities. Intellectual ability can often mask this, leaving individuals without the backup they require in order to thrive. At the 2007 forum 'Successful Futures for Adults

with Autism' participants' highlighted challenges around navigating social life, managing practical and financial affairs, accessing education and training opportunities, securing and maintaining employment, and good physical and mental health. Participants deemed existing models of support, often involving being part of a large group, stressful and inadequate. Many expressed preference for a one-to-one relationship (which could then be broadened over time), based on time-limited goal-oriented, specialist mentoring or life coaching.

What is Mentoring?

The Mentoring and Befriending Foundation (2014) defined mentoring as a time-limited goal-orientated relationship that supports both personal and vocational learning and development. Essentially an experienced person provides, within a trusting atmosphere, non-judgemental guidance and support to another (less experienced) person through a variety of methods including role modelling, guidance and problem solving (Western, 2012).

Specialist mentoring schemes for people on the autism spectrum are rare and very few have been subjected to good quality evaluations (Gelber et al., 2014). Schemes for mentoring University students on the spectrum are coming under scrutiny mainly because of changes to funding.

Research

The Research Autism Cygnet Mentoring project was a two-year pilot study, aiming to develop, trial and evaluate a mentoring scheme designed with input from autistic people, their families and supporters. Operating from an 'emancipatory research' standpoint, user involvement was central to the design of every aspect including outline design of the programme itself, recruitment of staff, mentor training, selection and supervision as well as fixed term paired mentoring and monitoring. Mentoring guidance was informed by Personal Construct Theory (PCT) (Kelly, 1955) and in particular the use of the Salmon Line (Salmon, 2003).

Methodology

Each participant received one hour of mentoring per week over a six-month period. The time frame was chosen following consultation of adults with autism by Research Autism, in which a preference was expressed for time limited, goal orientated mentoring over long-term 'befriending.'

Face to Face and email mentoring arrangements were implemented, based on participant choice. Mentee preferences, accessed via an expression of interest form/screening tool, informed the matching process as far as possible. Mentors and mentees could contact the researchers throughout the programme about any issues that they felt unable to resolve within their sessions. Additionally, mentors were invited to attend a peer support event around the third month of mentoring.

Recruitment

- All participants had the right to withdraw from the project.
- 2 mentees withdrew from participation.

Mentors

- All mentors received one day of training developed by the project team with input from the advisory and steering groups.
- All mentors who were accepted into the pool on mentors utilised for the project were interviewed for suitability and for matching with mentees.
- All mentors were required to obtain a disclosure from the Criminal Records Bureau (CRB) prior to commencing mentoring.

Mentees

- Difficulty recruiting mentees within the age range 18-24.
- Disability Services at Universities advertised the project.
- Difficulties recruiting may have been due to individuals within this age range already having experienced mentoring as a service at University.
- A referral form had to be made by the individuals themselves rather than somebody on their behalf, and therefore this age group may have found it difficult to acknowledge that they needed support.
- A decision was made to extend the age range of participants to 18+.

Data collection and analysis

A standardised tool, the PWI-A (2006) developed by the International Wellbeing Group at Deakin University in Melbourne, was used to measure changes in participants' perception of their own wellbeing before and after the six months of mentoring. The PWI-A allowed participants to rate their standard of living, personal health, achievement in life, personal relationships, personal safety, community connectedness, future security, spirituality and religion. This tool had been successfully used with autistic adults in an EU funded study (Autism in Pink, 2016).

Semi-structured interviews were conducted with both mentors and mentees after completion of the mentoring programme. Mentors made use of materials based on the Salmon Line techniques (tools used in PCT) (Kelly, 1955; Salmon, 2003) and the resulting data was also used to analyse mentee perceptions of their progress towards their goals. Mentors and mentees also completed a mentoring record sheet and reflective journal after each session. Thematic analysis (Braun & Clarke, 2006) was applied to all qualitative data.

External Scrutiny and Ethical Clearance

Ethical clearance was received from LSBU before any data was collected. The project was subjected to ongoing external scrutiny from steering and advisory groups in which the majority of members were autistic adults. A final scrutiny event will take place in September.

Findings

Key themes from thematic analysis of the rich data yielded by the project are summarised in brief here. All data has been carefully preserved to allow for further interrogation if funding permits.

Key themes:

Training

- The authentic voice of men and women with autism is an essential component.
- Two days would be preferable to one.
- Reliability must be emphasised in training alongside an understanding of boundaries and supervision.
- The role of the mentor in helping the mentee to set their own goals must be made clear throughout training and supervision.
- The accredited training that is available is not adequately evidence based and does not cover the components of understanding autism, mentoring and context.
- The acronym REAL ('reliable, empathic, anticipatory and logical') usefully encapsulates the values underpinning mentor training. (Hastwell et al., 2013)
- An outcome of the project could be to develop such training for CPD accreditation. A PG Cert in Autism Mentoring, accredited by LSBU, has been developed and validated already as a result of the project.
- Thought to be given to future evaluation using an evidence-supported

model

The need for supervision

- Supervision was a key area and we found much evidence of poor or unstructured supervision of mentoring in arrangements we identified.
- Finding a suitable mentor for each mentee was a complicated process and we had to strike a balance between the mentee's ideal choice and what was possible. Some mentees were hoping for friendships which overstepped the boundaries and this had to be handled with care and clarity.
- Mentors requested from supervisors, advice as to how best to support the mentee and how to deal with situations that may cross boundaries.
- Creating a range of ways in which mentors could bounce ideas off one another and provide peer-to-peer support would be a useful future development.
- On-going development as a mentor was important and the gap in suitable accredited and non-accredited training and CPD was highlighted.
- Processes for reporting issues of concern were strengthened during the project as these, although covered in training, were less clear than we had realised.

The need to set clear boundaries

- Issues around advocacy emerged in relation to the role of the mentor in facilitating support. It became clear that giving mentors a very clear steer on signposting needed to be more firmly embedded in training.
- Training emphasised the need for clear boundaries about what mentoring is and what it is not (e.g. befriending, coaching, and counselling). During the course of the research it became abundantly evident of the need to reinforce this in supervision.
- Two, and on one occasion three, layers of supervision emerged in practice. The researchers were the first line of supervision and would seek advice from the Principal Investigator who in one instance needed to clarify a situation with RA's Research Director. Clearly, supervisors need somewhere to go if they need advice and this should be built into a mentoring scheme.

Matching mentors with mentees

- The limited age range of available mentors meant that mentees could not necessarily have a mentor in their preferred age range.
- Lack of male mentors was an issue.
- One male mentee particularly wanted a young female mentor and concerns were raised as to whether this was because he felt that the mentor would be able to play an additional role of support in relation to understanding

females and relationships.

- Issue arose around communication, understanding, expectations and identity when matching a mentee with a mentor on the autism spectrum.

One mentee commented:

“Having a mentor on the spectrum has actually made me more insecure because whereas I thought I would be able to draw similarities between myself and the mentor, she seems a lot less far on the spectrum than me.”

This example highlights the requirement for closer supervision if both mentor and mentee are on the spectrum.

- It is important to note that the literature includes many examples of mentoring between people on the spectrum, which exists outside formal arrangements, and operate successfully.
- The reliability and consistency of mentors emerged as a fundamental concern. Although this was emphasised in training, a minority of mentors were unreliable and would cause the mentee stress by altering arrangements.

Flexibility of mentoring scheme

- The possibility to change mentors if the matching had not worked from the mentees perspective was built in but did cause mentees feelings of anxiety. In retrospect the ramifications should have been clearer
- The specificity of the project required mentees to set goals early and some had difficulty in understanding the concept of ‘life goals’. In a practical mentoring scheme more time could be allocated to making this idea clearer.

Dissemination

A large scale London based dissemination and evaluation conference is being planned for the autumn. The team has presented work in progress throughout at various events including the Autism Show, NAS Professional Conference, National Association of Disability Practitioners International Conference and the John Lewis Partnership. Further conference presentations will take place at Theorising Normalcy and the Mundane (Manchester), Disability Studies (Lancaster), Autism Europe (Edinburgh), and the NADP National Conference.

So far the team has published in the *Journal of Inclusive Practice in Further and Higher Education*, University of Birmingham book of conference proceedings, SHARE and Your Autism. Currently the researchers are writing for *Advances in Autism*, *Good Autism Practice* and *Disability and Society*. Subject to funding, further publications and conference presentations are possible from the data.

Limitations

Administration

- Funding did not allow for any administrative support for the project and fell to the research team. This placed additional demands and should be factored in to replication.

Training and subsequent recruitment of mentors

- The training events attracted people who were motivated by the fact that it was free and did not intend to progress to being interviewed for a mentor role. However their participation in the evaluation of the training was useful and the indirect benefit was that they are likely to be better mentors in other contexts because of the experience.
- Of those matched, the vast majority proved reliable.

Type of mentoring

- The mode of mentoring was the choice of the mentee but we found: some technical difficulty communicating via online messenger, and that maintaining boundaries was more of a problem when mentoring took place via email.
- The duration of mentoring was stressful for some mentees who found an hour too long. The opportunity to check in more briefly should be built into an operationalised scheme.

Key learning points

- Mentor schemes should not operate without formal systems of vetting, recruitment, training, support and supervision.
- Mentor selection needs to interrogate prior qualifications and experience of working with people on the autism spectrum and personal characteristics, such as respect for the autonomy of the mentee.
- Training needs to include an understanding of the boundaries of mentoring, supervision arrangements and process as well as high-quality respectful autism focussed input.
- Reliability must be emphasised in training.
- The quality of the training experience is enhanced when there is significant input from autistic people in its design and delivery.
- Having male and female autistic trainers was felt by trainees to provide

balance.

- Personal construct theory provided a sound framework in training for emphasising the role of the mentor in facilitating the mentee in setting and working towards their goals (set by mentees and facilitated by mentors when needed).
- Trainees felt that the face-to-face nature of the training was important and that the high quality material ideally required two days of input.
- There is a lack of evidence-based mentor training and ongoing supervision, which fulfils the conditions described above.
- Participants on the spectrum found their mentor experience very helpful in enabling them to progress toward self-identified goals.
- Mentees felt empowered by the person-centred methods employed on the project and in setting their own goals.
- Control of the way in which mentoring sessions were to be conducted was important to mentees who favoured a variety of approaches including face to face and email contact.
- The matching of mentor and mentee was viewed as an important factor in determining the effectiveness of mentoring.
- Boundaries were difficult to hold in situations where mentees were experiencing particular challenges, especially when mentoring was via email. It was necessary to address this during supervision usually by advising mentors to signpost to additional services.
- Occasional boundary concerns revealed the requirement for supervisors to have an adviser to call upon occasionally.
- A number of aspects of the mentoring project have been identified for further investigation, including: boundary setting, supervision, flexibility, and the matching of mentees with mentors.
- A larger scale action research project is required in order to build on the pilot with a view to operationalising a mentor scheme that includes the essential components identified.
- An evidence based mentoring scheme including training, supervision and CPD is required and the team is well placed to develop this. We have already created training and a validated PG Cert. The next step is to ensure that the training protocols are approved for professional CPD.

Conclusions

The project has highlighted the benefits of time limited goal orientated mentoring and the lack of a rigorous evidence base underpinning current mentoring practice with adults on the autism spectrum. It also suggests that to offer mentoring to this group outside of a formal supervised structure without training and support is reckless and potentially harmful. The current situation is at best patchy.

Inadequate supervision of mentors is a particular concern, as is the lack of clarity on boundaries with regards to mentoring support. Training does not currently appear to be required and where it is offered it is unclear as to whether this offers the essential safeguards or informed by the autistic perspective.

Next steps

In order for the project to realise its emancipatory aim of ultimately producing an intervention informed by, and practically useful to people with autism, the following steps are proposed:

Secure funding for action research that will:

- Develop the training programme into a two-day model that can be delivered by the current trainers and is approved for CPD.
- Identify additional trainers who could be trained to deliver the two-day training and a means of inducting and supervising new trainers, to include well-qualified men and women on the spectrum.
- Research and develop a form of accreditation for the training that is externally validated.
- Deliver 8 further two day accredited training sessions over one year.
- Further develop standardised paperwork and online materials for recording mentoring sessions.
- Develop systems for ongoing regulation and supervision of mentoring and an umbrella under which the scheme could sit. Ongoing CPD would need to form part of the scheme.
- Recruit eight cohorts of six mentor mentee pairs and repeat the pilot in its new form with the additional training and revised regulation and supervision systems.
- Trial and evaluate the larger scale programme over two years as an action research project.
- Evaluate with a view to ethically commercialising the scheme in two years time based on the findings.

Note: Currently BiS is seeking to formalise its engagement with DSA funded mentors and this project has something very tangible to offer in this regard. In addition, Personalised Budgets could be utilised to secure good quality regulated mentoring effectively.

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