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## **A review of mentoring guidance for students on the autism spectrum**

**Damian E M Milton and Tara Sims**

### **Abstract**

This paper reflects upon the initial stages of a project being conducted at London South Bank University (LSBU) regarding mentoring for young adults who are on the autism spectrum, locating problematic issues with current guidance, before giving an overview of the proposed project and its methodology. 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 (VanBergeijk et al. 2008, Gelbar et al. 2014). Where there are some possibly valuable insights in such accounts, they would be open to criticism by a number of autistic scholars and activists (Milton, 2012a, 2014). Upon review of current practice guidance, this project will offer an alternative to student mentoring guided by the Personal Construct Theory (PCT) of George Kelly (1955).

### **Background rationale for the mentoring project**

Adults on the autism spectrum who are highly verbal can have nuanced support needs that can go unrecognised within both educational and work settings. At the 2007 forum 'Successful Futures for Adults with Autism' participants highlighted difficulties experienced with navigating social life, including: managing their own practical and financial affairs, accessing education and training opportunities, securing and maintaining employment, and maintaining good physical and mental health. There was a common feeling that existing models of support for adults on the autism spectrum, which often involve being part of a large group of people, were not helpful. Many described how they felt stressed or unsure in such surroundings, preferring a one-to-one relationship which could then be broadened over time. Many said that they would only want this support on a time-limited basis, but that it should be goal-oriented, specialised and based on a personal life coach or mentor model. Many participants said they would like to use the allowances they received for personal support to pay for such services, but few had access to such services in their locality.

## **What is known about mentoring generally.**

According to *The Mentoring and Befriending Foundation* (2014), mentoring is a time-limited goal-orientated relationship that supports both personal and vocational learning and development. It involves an experienced person providing guidance and support to another (less experienced) person through a variety of methods (Western 2012). There is therefore a necessity for the mentor to have an understanding of the mentee's social world and perspective, as well as the necessary 'people skills' to share their experience in an effective and helpful way (Western 2012).

Mentoring can occur either formally or informally (Miller 2002). Informal or 'natural' mentoring can be said to develop within all kinds of social relationships, whereas formal or planned mentoring operates within a structured programme with clear objectives, where mentors and mentees are matched. Planned mentoring can vary vastly depending on the institution in which it is delivered and the philosophy guiding its practice, but there are usually some shared characteristics, described by Miller (2002) as including:

- It is a deliberate, conscious and voluntary relationship.
- It may or may not be time limited.
- It is supported by an organisation.
- It occurs between an experienced person and one or more other (less experienced) persons.
- It is not hierarchical.
- The relationship is expected to be beneficial to both mentor and mentee.
- It will typically include elements of interpersonal support, guidance, mutual exchange, sharing of wisdom, and coaching.

Despite these characteristics, both mentors and mentees are involved in negotiating the form of their responsibilities within the relationship and are therefore involved in defining what mentoring is and what mentors do (Miller 2002).

## **Mentoring in the context of autism.**

Both Access to work and student mentoring for people on the autism spectrum is available through various schemes in the UK, yet specialist schemes are rare and research on the topic rarer still. The only area of mentoring for people on the autism spectrum to have begun to gain the attention of researchers has been student mentoring schemes for College and University students. Gelbar et al. (2014) conducted a systematic review of articles describing the experience and support schemes made available for people on the autism spectrum attending College or University. This review only found twenty articles referring to sixty-nine people in total, with only two of these studies being 'experimental' in nature, neither of which were evaluating a mentoring scheme. The other eighteen studies were all individual case study reports. Such a scarcity of research into the area indicates a genuine need for this pilot study to be conducted.

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. 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 clinicians perspective, suggesting 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). There are some potentially valuable insights in such accounts, such as smaller settings and class sizes, and utilising strengths and areas of interest. By taking a medicalised deficit model view of autism, however, they also recommend strategies such as role playing, generalising, teaching people on the spectrum to recognise their own emotions through explicit instruction, and so on, which would be much criticised by a number of autistic scholars and activists (Milton, 2012a, 2014).

### **Autism and wellbeing**

Where studies have used wellbeing indicators with adults on the autism spectrum, one often finds much lower self-assessments (Bracher, 2014). Yet, it is debatable to what extent standardised measures of wellbeing capture autistic experience and sensibilities. *"Most scales devised for use with the general population cannot be used with all population sub-sets"* (International Wellbeing Group, 2006, p. 5).

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 (Jones and Hurley, 2014). A number of studies have shown the potential of utilising Personal Construct Theory (PCT) (Kelly, 1955, Salmon, 2003) with autistic populations however for gaining a clearer insight into the perspectives of autistic participants (Moran, 2006, Williams and Hanke, 2007, Milton, 2012b, Greenstein, 2013).

### **Aims / Objectives**

This two-year pilot study has been funded to establish a mentoring scheme, designed with input from people on the autism spectrum and their families and supporters, and evaluate its effectiveness in improving the wellbeing of young adults on the spectrum between the ages of 16-24. Considering this in conjunction with the previous discussion has resulted in the following aims and objectives.

- Aim One: To develop an excellent sustainable research-informed mentor training programme:
  - Objective 1a: To review existing training for mentors of people on the autism spectrum;
  - Objective 1b: To develop a mentor training programme with input from adults on the autism spectrum;
  - Objective 1c: To develop accompanying paperwork for the programme that has the potential to be distributed and used in different contexts both nationally and internationally.
- Aim Two: To assess the effectiveness of the mentoring programme developed for young adults on the autism spectrum:
  - To assess whether mentoring impacts on goal achievement and satisfaction for mentors and mentees;
  - To assess whether it has any impact on the quality of life of both mentors and mentees using both qualitative measures (interviews and diaries) and a standardised survey tool (the Personal Wellbeing Index - Adult , PWI-A, International Wellbeing Group 2006);

- To use qualitative interviews to gain an understanding of participants' perceptions of the mentoring programme in order to improve the programme based on the views of those involved.

### **Study Design (methodological approach)**

It has been argued that traditional research in the social sciences has perpetuated unequal power relationships experienced by groups of people who have historically experienced marginalisation in society, with research being done “to” rather than “with” people (Barnes & Sheldon 2007). The 'emancipatory' research paradigm purports that the participants of research should have involvement with and control over the research agenda and process (Barnes & Sheldon 2007). Furthermore, the overall aim of 'emancipatory' research is to empower its participants and bring about a positive change for them, as opposed to for the benefit of researchers or institutions (as in traditional research) (Barnes & Sheldon 2007).

The proposed research will be carried out in line with principles of 'emancipatory research', using mixed methods. This will enable the generation of in-depth qualitative data that will facilitate an understanding of participants' views on the value of mentoring generally and this mentoring programme specifically. Additionally, quantitative data on the overall impact of mentoring on the well-being and goal achievement/satisfaction of mentors and mentees will be gathered.

Operating from an 'emancipatory research' standpoint, user involvement is central to the design of this project and its activities. The mentoring scheme will be designed by people on the spectrum, including a member of the research team and an advisory panel. It will be evaluated by mentors and mentees, and this evaluation will be informed by PCT (Kelly, 1955, Salmon, 2003).

The research will be conducted in part by people on the autism spectrum, and led by a researcher who has personal experience of autism; it will be interpreted within the intellectual framework of that group, and conducted largely for the purpose of empowering people on the autism spectrum and improving services. Such a

mentoring model based upon these principles has the potential to provide invaluable guidance and be of great benefit to this group of people.

## **Methods**

### **Sampling**

Stratified opportunity sampling will be used to ensure a spread of ages of mentees. The following participant numbers will be selected from respondents (on a “first come first served” basis):

- Mentors – 12 (no age range specified);
- Mentees aged 16-18 (inclusive) – 4;
- Mentees aged 19-21 (inclusive) – 4;
- Mentees aged 22-24 (inclusive) – 4.

### **How the project will be conducted**

The project will study the impact of access to mentoring on the wellbeing of twelve young adults on the autism spectrum. Each participant will receive one hour of mentoring per week over a six month period. A period of six months has been chosen because of the view expressed by adults on the autism spectrum in the Research Autism consultation, that a short-term mentoring scheme would be most effective for them, and that they would not be looking for a long-term ‘befriending’ style of relationship, but short-term goal oriented support to help them move on with their lives. It is expected that the time period will be sufficient, but if the project finds that six months is not enough, which would be a useful finding in itself, we aim to extend the mentoring on a time-limited basis if potential for future benefit is identified.

A variety of mentoring arrangements are likely to be implemented in this project, including face-to-face interactions and email based interactions depending on the preferences of the participants. For some participants access to funded mentoring is possible. For example, some adults on the autism spectrum receive mentoring within the context of a package of support in College or University, or through an

Access to Work grant. Where no such arrangements are available the project would recruit people who already have experience of supporting people on the autism spectrum and then train them as volunteer mentors. These differing arrangements and the constraints they have on the mentoring process will be taken into account in both the design and evaluation of the mentoring training and model utilised. Built into the budget for the project will be the expenses incurred by volunteer mentors. Mentors and mentees will be matched as guided by the mentees' goals for mentoring, which they will identify on their expression of interest form/screening tool. All mentors and mentees will be able to contact the research team during the programme in case of any issues that they feel unable to resolve within their mentoring sessions. Additionally, mentors will be invited to attend a peer support session approximately three months into the mentoring programme.

### **Data collection and analysis**

The research team will employ the standardised tool, the PWI-A (2006) developed by the International Wellbeing Group at Deakin University in Melbourne, to measure changes in participants' perception of their own wellbeing prior to, after, and six months after completion on the mentoring programme. This tool asks participants to rate their standard of living, personal health, achievement in life, personal relationships, personal safety, community connectedness, future security, and spirituality and religion. An added measure of 'control and autonomy' will also be utilised due to this issue being highlighted in the literature review.

This data will be supported by qualitative indicators from a number of data collection methods. Semi-structured interviews will be conducted with both mentors and mentees after completion of the mentoring programme. The mentors will also be given materials based on the Repertory Grid and Salmon Line techniques (tools used in PCT, Kelly 1955, Salmon 2003) as part of their guidance materials to utilise with participants through the mentoring programme that can be used to analyse progression from the subjective viewpoint of the participants. Additionally, mentors and mentees will be asked to complete a mentoring record sheet and reflective journal after each mentoring session. Qualitative data will be analysed using thematic analysis (Braun & Clarke 2006).



## **Conclusion**

The support needs of adults on the autism spectrum may include managing practical and financial affairs, accessing education, training and employment, and maintaining good physical and mental health. These needs, however, often go unrecognised, with adults on the spectrum reporting that current modes of support do not meet identified needs. Mentoring is a time-limited goal-orientated relationship that supports both personal and vocational learning and development and may, therefore, be an appropriate model of support for autistic adults seeking to engage with student mentoring services or Access to work schemes. Specialist mentoring schemes for people on the autism spectrum are rare however and focus mainly on the university setting, with guidance written from the perspective of clinicians. Furthermore, research on the topic is even rarer. This has led to a two-year pilot study being funded to establish a mentoring scheme for young adults on the spectrum between the ages of 16-24, designed with input from people on the autism spectrum and their families and supporters. Its effectiveness will be evaluated using both quantitative and qualitative methods, framed within an 'emancipatory research' context and guided by personal construct theory.

## **Biography**

**Tara Sims** completed a BA (Hons) in Developmental Psychology at Sussex University, and then trained as an occupational therapist (OT). She recently completed her PhD in Health Sciences at the University of Southampton. Alongside working on this project, Tara works as an OT in an integrated child development and disability service.

**Damian Milton** is studying for a doctorate at the University of Birmingham. He is a member of the programme board for the Autism Education Trust, and a member of the scientific and advisory committee for Research Autism. Damian works for the National Autistic Society as Head of Autism Knowledge and Expertise (adults and community) and London South Bank University as a Research Assistant.

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