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**Does 'mentoring' offer effective support to autistic adults?:
a mixed methods pilot study**

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Introduction

The Research Autism Cygnet Mentoring project was a two-year pilot study, completed in 2016, which aimed to develop and evaluate a mentoring scheme designed with input from autistic people, their families and supporters. 'Emancipatory research' (Barnes and Sheldon, 2007) principles underpinned every aspect of the project, which meant that user involvement was central to the design throughout, including: outline design of the programme itself, recruitment of staff, mentor training, selection and supervision as well as fixed term paired mentoring.

The Mentoring and Befriending Foundation (2014) defines 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). There is no published research exploring mentoring and employment for people on the autism spectrum and only one systematic review which examines the evidence for mentoring in post compulsory education for people on the autism spectrum. **Gelbar et al.'s (2014) systematic review of articles describing the support schemes made available for people on the autism spectrum attending College or University found only 20 articles, which referred to 69 participants in total. Only two of the studies were 'experimental' in nature, neither of which evaluated a mentoring scheme. The other 18 studies were individual case study reports. However, Gelbar et al. (2014) did conclude that, although the evidence is limited, experiences of post-compulsory education described in the studies included isolation, loneliness and problematic mental health, highlighting a need for better support.**

The support requirements of intellectually able autistic adults can be just as nuanced as those for people who have significant learning difficulties/disabilities (Fabri et al. 2016). Intellectual ability can often mask this, leaving individuals without the support they require in order to thrive. At the Research Autism 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. Overwhelmingly, those who contributed deemed existing models of support, often involving being part of a large group, to be stressful and inadequate. A concluding recommendation from this forum was an 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'.

Two overwhelmingly important drivers for the need for mentoring are mental wellbeing, and unemployment. Regarding the former, a number of studies now show that adults on the autism spectrum have relatively high rates of anxiety, depression, and suicidality (Hirvikoski, et al. 2016). This is likely to be a result of feeling isolated and excluded in society (Milton and Sims, 2016; Pelton and Cassidy, 2017). Regarding the latter, the National Audit Office's (NAO, 2009) report *Supporting People with Autism through Adulthood* highlighted that only 12% of respondents of the NAO survey were in full-time paid employment; and 70% identified mental health problems. These figures are also supported elsewhere (NAS 2017), although they are likely to underestimate the numbers of non-identified people on the autism spectrum in employment (Brugha et al, 2011). The motivation behind the present mentoring study was to evaluate if mentoring might serve as an effective intervention to promote mental wellbeing and greater levels of employment in adults on the autism spectrum.

Given resources, the present study could not be designed as a large scale quantitative randomised control trial. Instead, it was set up as a small mixed -methods preliminary pilot study in order for the research funder and research team to learn what the issues were, with a view of gathering information and preliminary evidence that would be needed in the event of a large scale study.

Methodology

Ethics

Ethical clearance was obtained from London South Bank University (LSBU) before any data was collected. Autistic involvement based on the emancipatory and ethical principle of 'Nothing about us without us' underpinned the project. This was evident in the project's development being based on the views of participants who attended the 2007 forum 'Successful Futures for Adults with Autism'. Furthermore, a key member of the research team is autistic and the project was subjected to ongoing external scrutiny from steering and advisory groups in which the majority of members were autistic adults. Recruitment interviews for the research team included 50percent autistic representation.

All participants were provided with Participant Information Sheets detailing the requirements of participation in the project and had an opportunity to have their questions about the project answered, before providing written informed consent. All participants had the right to anonymity and to withdraw from the project at any stage. In practice, 3 mentees withdrew. Reliability of mentors and clear communication were an ethical concern throughout the project, particularly given that ambiguity has the potential to cause high levels of stress, particularly for autistic people. We sought to reduce the anxiety by being as clear as possible but observing essential ethical boundaries around the ability to withdraw may have added a degree of uncertainty for some mentees.

Advertising and Recruiting

Mentoring has been defined in the introduction to this paper. It is important to be precise about this as the term means different things to different people. Boundaries between mentoring, befriending, counselling and coaching type relationships are often confused and the terms conflated. From the start of this project the definition of mentoring (based on the Mentoring and Befriending Foundation's (2014) definition), and participant requirements, were made explicit to all those who expressed an interest. Clarity is vitally important for autistic people (Povey, 2015) and in the construction of research.

Potential mentors and mentees were targeted initially via advertising through the National Autistic Society (NAS), Research Autism (RA), the National Association of Disability Practitioners (NADP) and the Disability in Education Research Network (DERN) websites, as well as universities and colleges. Further and Higher Education was identified as a probable source of autistic mentees within the student body, as well as disability support practitioners and researchers interested in autism who may have wished to become mentors.

Recruitment of mentees within the originally defined age range of 18-24 proved more difficult than expected with more applicants from an older age group. It was therefore decided to extend the age range of participants to 18+. In the event this was serendipitous. Adults are most likely to be engaged in post compulsory education where opportunities to access mentoring may be available via The Disabled Student Allowance (DSA) and similar. Mentoring services for older adults (who are not mature students) are less common. Parents, and in one case a sister, approached the project, but the design dictated that a referral must be made by the individuals themselves rather than somebody on their behalf. In hindsight this requirement could have created an unintentional barrier to participation. It may also be that some autistic individuals who could have benefitted would have found it difficult to acknowledge that they needed support, or to navigate the application process. The research team acknowledge that, in an attempt to preserve the autonomy of autistic potential mentees, barriers to participation may have been created for some. This is a lesson for future projects.

Parameters of the project were made explicit partly to avoid raising expectations of mentees and to ensure that everyone who chose to be involved knew what to expect. All mentors and mentees were informed that they would be expected to participate in one hour of mentoring per week over a six-month period, and required to complete evaluation activities. As stated earlier ethical protocols also emphasised the right to withdraw from the study making for an awkward juxtaposition between committing to and withdrawing from it. This is not uncommon.

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3 Mentor training and introductory activities preceded the mentoring intervention and
4 participation in training and an interview was mandatory for all mentors without exception
5 and regardless of prior experience, in order to preserve the integrity of the study. All
6 potential mentors received one day of training developed by the project team with input
7 from the advisory and steering groups. The training has been evaluated and developed
8 based on participant feedback and the findings from this evaluation have now been
9 published (Milton et al. 2017). Based on evaluations of the training a two-day model has
10 now been developed. National accreditation via the CPD standards office has been obtained
11 and the training is being delivered nationally by accredited trainers from the original project.

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16 Those accepted into the pool of mentors were interviewed for suitability and for matching
17 with mentees. This is important. Those who attended training did not automatically become
18 mentors for a variety of reasons, including not putting themselves forward and not being a
19 good match for any of the individuals within the particular group of mentee participants. All
20 of those accepted were required, for ethical reasons, to obtain a disclosure from the
21 Criminal Records Bureau (CRB) prior to commencing mentoring.
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25 *The mentoring sessions*

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28 The time frame for the series of mentoring sessions was chosen following consultation of
29 autistic adults by Research Autism, in which a preference was expressed for time-limited,
30 goal-orientated mentoring rather than a more open ended and potentially long-term
31 'befriending.' Befriending as a concept had been identified as problematic by a number of
32 participants at the initial forum. Face-to-face and email mentoring arrangements were
33 established and implemented, based on participant choice.
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37 Mentee preferences, accessed via an expression of interest form / screening tool, informed
38 the matching process as far as possible. Boundaries were made explicit to both parties from
39 the start through use of a mentoring agreement, signed by both parties, which stated:
40 mentoring was to take place once per week for one hour; all meetings were to take place in
41 a public place and never in a mentor or mentee's home; contact between meetings was only
42 to occur for the purposes of altering details about the next meeting; and meetings were to
43 be cancelled only when absolutely necessary, with as much notice as possible being given.
44 Supervision and ongoing support was built in. Mentors and mentees were clear about how
45 to arrange and document sessions and could contact the researchers throughout the
46 programme about any issues that they felt unable to resolve within their sessions.
47 Additionally, mentors were invited to attend a peer-support event around the third month
48 of the mentoring scheme. Researchers were clear about their ongoing responsibilities, both
49 for collecting data and monitoring the programme, during the period of time in which the
50 pairs were meeting. All participants had full capacity and were adults at the start of the
51 project.
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3 Mentoring guidance was informed by Personal Construct Theory (PCT) (Kelly, 1955) and in
4 particular the use of the Salmon Line (Salmon, 2003). PCT was developed by Kelly (1955) in
5 response to inadequacies he saw in the focus on the unconscious mind within
6 psychoanalysis and or environmental conditioning in behaviourist approaches to
7 counselling. Kelly (1955) was instead interested in the subjective personal constructions
8 people used to make sense of their experiences. This approach supported the person--
9 centred ethos of this project and was utilised in an attempt to reduce difficulties that can
10 ensue due to mutual incomprehension between autistic and non-autistic people within
11 interactions (Milton, 2014; Sheppard et al. 2016; Sasson et al. 2017).
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16 With regard to the setting of educational goals, Salmon (2003) used PCT to devise the
17 'Salmon line' tool. This simply requires the drawing of a line. The student is then asked to
18 write at one end of the line, what it would look like to be satisfied with a goal, and what it
19 would look like to completely dissatisfied at the other end, and then to place oneself on the
20 line regarding where one felt one currently sat. This gave the educational tutor space to
21 explore with their student practical ideas that could lead to goals being attained, as well as
22 potential barriers which could hold that back or even reverse progress. The use of this tool
23 was adapted for use in the project and informed part of the mentor training, with the line
24 being divided on a scale of 1-10 for data collection purposes.
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29 *Data collection*

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31 A well- used standardised tool, the PWI-A (2006) developed by the International Wellbeing
32 Group at Deakin University in Melbourne, was used to measure changes in participants'
33 perception of their own wellbeing before and after the six months of mentoring. The PWI-A
34 allowed them to rate their standard of living, personal health, achievement in life, personal
35 relationships, personal safety, community connectedness, future security, spirituality and
36 religion. This instrument had been successfully used with autistic adults in an EU funded
37 study (Autism in Pink, 2016) who related well to its structure. The PWI also allows for same
38 age and within-country comparison of subjective wellbeing. Subjective wellbeing is
39 particularly important in autism as quality of life assessed on quantitative, normative
40 measures may not resonate as well with many autistic individuals.
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46 Semi-structured interviews were conducted with both mentors and mentees after
47 completion of the mentoring programme. Mentors made use of materials based on the
48 Salmon Line techniques (tools used in PCT) (Kelly, 1955; Salmon, 2003). Resulting data was
49 also used to analyse mentee perceptions of their progress towards their goals, using a scale
50 of 1-10 as well as open ended comments. Mentors and mentees also completed a
51 mentoring record sheet and reflective journal after each session to provide further data.
52 Thematic analysis (Braun & Clarke, 2006) was applied to all qualitative data.
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56 **Findings**

Of the 12 initial matched pairings, 9 completed the project and 3 did not fully complete all of the post-intervention data collection exercises, although they did provide the project with useful partial data.

Personal wellbeing index (PWI) scores

Table 1 shows the initial PWI scores of all mentees, the initial scores for those who finished the program, the post-intervention scores, and the average difference recorded pre and post intervention (for those who completed the program).

Table 1: Average PWI scores

PWI	All – pre-intervention	Pre (who finished)	Post	Difference
Thinking about your own life and personal circumstances, how satisfied are you with your life as a whole?	5.1	6	7.8	1.8
How satisfied are you with your standard of living?	6.4	7.6	7.4	-0.2
How satisfied are you with your health?	5.9	6.8	7.6	0.8
How satisfied are you with what you are achieving in life?	5.1	5.4	7	1.6
How satisfied are you with your personal relationships?	5.1	5.8	6	0.2
How satisfied are you with how safe you feel?	6.4	7.4	8.8	1.4
How satisfied are you with feeling part of your community?	5.3	7.5	7.5	0
How satisfied are you with your future security?	5	6	6	0
How satisfied are you with your spirituality or religion?	6.25	8	8.5	0.5

All mentees completed an initial PWI questionnaire and six repeated this exercise at the end of the programme. Of those who started, average scores ranged from 5 to 6.4 for the various aspects of the measure. Satisfaction with life as a whole averaged 5.1 out of a possible 10. Those who completed the programme showed a higher initial level of wellbeing with scores averaging between 5.4 and 8 and an average satisfaction with life as a whole of 6 out of 10. Upon finishing the mentoring programme, there were improved scores in a number of areas, interestingly in how satisfied mentees were, how safe they felt (+1.4 on average) and with their health (+0.8 on average). The biggest improvements were found in satisfaction with what the mentees were achieving in life (+1.6 on average) and with satisfaction with life as a whole (+1.8 on average).

Table 2 below shows the average satisfaction with goals recorded using the Salmon Line tool (again – pre-intervention for all and for those who finished the program, post-intervention and the average difference in score).

Table 2: Average progress toward goals

All – pre-intervention	Pre (who finished)	Post	Difference
3.75	4	8	4

Prior to the mentoring program participants rated their average satisfaction with their selected goals at 3.75 out of 10, and 4 out of 10 for those who completed the program. For those who finished the project, average satisfaction with all three goals had risen to an average of 8 out of 10, a difference of +4 between all participants. This suggests that whilst the majority of mentees did not fully reach their goals, they did feel that they made significant progress toward them. One participant in particular made significant progress, having rated their satisfaction with goals at 3, 2 and 1 out of 10, by the end of the program this rose to 9, 8 and 9 out of 10 respectively.

Feedback from mentors

Training

A detailed report on the mentor training is provided in a separate paper (Milton et al. 2017).

The training is seen as an essential part of the programme and was able to deal proactively with issues that arose during the mentoring sessions, such as boundaries and conflicts as well as the value of evaluation.

Mentor Support and Supervision

Mentor supervision was integral to the design of the project. Ongoing supervision from the research team was built in and the majority of mentors chose to access this via email and telephone contact rather than face-to-face. This was due to other commitments or geographical distance. Seven mentors were able to make a mid-point mentor peer support session and all reported that they found it extremely useful.

All mentors accessed support from the project team at some point within the program – and all agreed or strongly agreed that this met their needs. Such backup and supervision is not typical of autism focussed mentoring schemes and this is a cause for concern, not only to the project, but also in relation to Disabled Student Allowance (DSA) funded mentoring.

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"It was really useful to have this support provided by somebody who was experienced as a mentor as she was able to understand the situations I was encountering and could advise me from the point of view of having experienced them herself – in effect 'mentoring' me as a mentor." (Pair 3)

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"I knew that...[the researchers]...were available if I had an issue which was enough support for me. However, if I had not felt so comfortable to approach them myself, a formalized supervision arrangement would have been needed." (Pair 3)

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The study suggests careful recruitment and selection, ongoing supervision, support and CPD, as well as rigorous initial training for mentors, are essential components of an ethical and useful mentoring scheme. External validation for training and subsequent CPD was built in to the pilot and is a requirement for staff working as mentors in the university sector.

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Feedback from mentors

What did you gain most from being a mentor?

All mentors agreed or strongly agreed that they had met their own goals on the project. Mentors described gaining satisfaction from helping others achieve their goals and from building rapport with mentees, as well as gaining personal confidence,

"The satisfaction of having beneficially affected someone's life, and the knowledge for how I can go on to support other autistic young adults." (Pair 1).

What did your mentee gain most from you?

Three mentees who had autistic or 'neurodivergent' mentors appreciated the perspective, empathy and role-modeling, of their mentor who demonstrated the possibility of managing life well. However, one mentee did not form as strong a connection despite their mentor being on the spectrum. This mentee described experiencing problematic persistent differences in understanding and communication.

Themes that emerged from mentee feedback were around: meeting goals, raising self-esteem, having a non-judgmental person to talk to, and acquiring work.

The Salmon Line

Although half the mentors found the Salmon Line tool of use, half found it less so in practice, despite the concept and tool receiving positive feedback from the initial training.

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3 The subjective and relatively vague nature of the exercise, were cited by those mentors who
4 were not enthusiasts. Mentors who found the Salmon Line useful used it as a reminder of
5 progress.
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8 The researchers concluded that the Salmon Line could be used alongside a range of other
9 tools in mentoring, and found it useful as a data collection tool for ascertaining progress
10 towards stated goals.
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13 *Feedback from mentees*

14 *Usefulness and benefit*

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19 *"I felt part of something important. I felt on the fringe of a wonderful network of*
20 *erudite academics. I met my mentor (now peer). It was human contact during very dark*
21 *days. It rebuilt my self esteem and self worth."* (Pair 5).
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25 All mentees completing the program strongly agreed that the mentoring was beneficial.
26 Four agreed that the Salmon Line tool was of use, whilst two did not. Whilst five strongly
27 agreed to finding the reflective logs helpful, one participant however, strongly disagreed
28 that these were a useful thing to do.
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31 Two mentees would have preferred more face-to-face contact with mentors, and data
32 collection systems which were easier to understand, and one commented that they would
33 have liked more visible (rather than background) support being shown by the project team
34 to mentors. Two mentees felt that supervisory support for mentors needed to be more fully
35 explained to mentees too.
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39 *Qualities of a good mentor*

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42 Personal qualities such as being non-judgmental and reliable were highlighted by mentees:
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45 *"Not scary, not intimidating, not hard to talk to, not someone who makes you feel*
46 *uncomfortable to be around them."* (Pair 8).
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49 *"Overall the most important thing was the consistent weekly 'lifeline' at a time when*
50 *my life literally fell apart. Even though I was going through a fundamental change (and*
51 *not coping), there was a weekly reminder to make progress towards bigger goals.*
52 *Without this I would have been like a ship without anyone at the helm (mentor)*
53 *or chart (goals) in a storm."* (Pair 5).
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57 *"It gives the mentee a safe way to practice social interaction without fear of the*
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3 *consequences of saying something wrong that you would have with family, friends or*
4 *work colleagues. Young people with autism can become very anxious even in the*
5 *simplest of social interactions at times, so having a safe place to find what works and*
6 *what doesn't through personal experience is very important." (Pair 1).*
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10 Mentees generally felt that mentors needed to be well-organised at arranging sessions, a
11 good listener, non-judgmental, flexible, and should know about the interests of the mentee.
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14 *"Before I just used to get overwhelmed and beat myself up. Now I know that it may be*
15 *because I am overwhelmed due to others lack of accommodation, or tiredness etc. not*
16 *necessarily my own failings." (Pair 5).*
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18
19 One mentee was irritated that their mentor 'broke stated rules, turned up late to sessions,
20 sometimes cancelled sessions, and did not provide enough structure'. Reliability of mentors
21 is fundamental to the success of a mentoring agreement, and, although this was
22 emphasized in training, this feedback highlights the need for further ongoing monitoring.
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25 26 *The importance of matching mentors with mentees*

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28 Matching of mentors with mentees is a complex and vital process and the research
29 highlighted a whole range of important considerations which hinged around a commonality
30 of understanding between the mentor and the mentee, including understanding the
31 purpose and boundaries of the mentoring role.
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35 *"I think matching mentor and mentee is one of the most important aspects. Obviously I*
36 *understand that this is difficult because you might not necessarily get the right person*
37 *applying to be mentors. I had asked for someone of a similar age to me. This wasn't*
38 *possible and my mentor was a lot older than me – I think this made it a lot harder for*
39 *me to relate to her and develop a positive relationship. It was OK for the job goal. But*
40 *for the more personal goals, particularly around my social difficulties it made it very*
41 *hard." (Pair 8).*
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45 46 *Progression toward goals*

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48 One mentee felt that they made slow progress toward their goals, while four felt that they
49 had made tremendous steps forward:
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52 *"...this helped me dig my way out of a life threatening hole that I could not see any*
53 *way out of. It reminded me to make progress towards goals. [The mentor] Listened*
54 *when I needed it, was a regular weekly marker in my chaotic life, provided an*
55 *opportunity to reflect and plan and self manage. I wouldn't have done this otherwise."*
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3 (Pair 5).
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6 Changes in PWI scores may well suggest that mentoring when working optimally can have a
7 marked effect on subjective feelings of well-being, although other factors beyond the
8 mentoring experience could have played a part and could not be isolated from the research.
9 For the three mentees with the lowest PWI scores who did not fully complete the program,
10 arguably mentoring was less successful. Again, factors beyond the study cannot be isolated
11 or interrogated fully. It may be that advocacy or other forms of support in addition to
12 mentoring may have been helpful in addressing some difficult life experiences which
13 possibly required more in depth intervention. Again, the issue of boundaries around
14 mentoring and what it can and can't do to assist an individual, are important and require
15 careful understanding. Accessing a range of services or approaches in tandem may be
16 beneficial but could have drawbacks, especially if it increases ambiguity.
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21 22 *Support from project team* 23

24 Whilst two participants would have liked more contact with the project team, four felt that
25 they were well supported throughout the project:
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28 *"She was generally very quick responding to emails and was very nice when we*
29 *met and answered some of my questions about the mentoring."* (Pair 8).
30
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32 **Discussion of practicalities and recommendations arising from the project** 33

34 35 *Training* 36

37
38 The training, although well received (Milton et al. 2017) and influential on the mentoring
39 practice, was somewhat overly constrained by being delivered over a single day. The
40 materials were designed however to be adaptable, and a two-day model has been devised.
41 A number of nuanced points came out from the mentoring practice that will influence how
42 this training is developed in future however. Firstly, although the reliability of mentors was
43 highlighted in the training, this needs be more strongly emphasised due to the detrimental
44 effects it can have on the experience of mentoring when a mentor is unreliable. Similarly,
45 the need for the mentor in helping the mentee set their own goals needs to be highlighted.
46 A strong feature of the training for attendees was the design and the delivery of the training
47 having significant involvement from the authentic voices of autistic people.
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53 Accredited training should be adequately evidence-based and research informed and needs
54 to cover the components of understanding autism, mentoring and context. An outcome of
55 the project was to develop the training for Continuing Professional Development (CPD)
56 accreditation. A Postgraduate Certificate in Autism Mentoring, accredited by LSBU, has also
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3 been developed and validated as a result of the project. Thought needs to be given to future
4 evaluation using an evidence-supported model and capturing evaluative data from all CPD
5 activity arising from the project. A short form of the training and a refresher model would
6 be worth considering for the future.
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9 10 *The need for supervision and boundary setting*

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12 Finding a suitable mentor for each mentee was a complicated process and we had to strike a
13 balance between the mentee's ideal choice and what was possible. Some mentees were
14 hoping for friendships which overstepped the boundaries and this had to be handled with
15 care and clarity. Preparation of potential mentees for mentoring is a key consideration for
16 all mentoring schemes. Supervision was also a key area and we found evidence of poor or
17 unstructured supervision of mentoring in discussions with groups doing the mentor training.
18 On a number of occasions, mentors requested advice from supervisors as to how best to
19 support their mentee and how to deal with situations that may cross established role
20 boundaries.
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26 Processes for reporting issues of concern were strengthened during the project as these,
27 although covered in training, were less clear than we had initially realised. Ongoing
28 development as a mentor was important and the gap in suitable accredited and non-
29 accredited training and CPD was highlighted and at least has now been partially addressed.
30 Creating a range of ways in which mentors could share ideas with one another and provide
31 peer-to-peer support through say a 'community of practice' would be a useful future
32 development.
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37 Issues around advocacy emerged in relation to the role of the mentor in facilitating support.
38 It became clear that ensuring mentor clarity on signposting, boundaries, coaching and
39 counselling needed to be more firmly embedded in training and frameworks for supervision.
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42
43 Two, and on one occasion three, layers of supervision emerged in practice. The researchers
44 were the first line of supervision and would seek advice from the Principal Investigator who
45 in one instance needed to clarify a situation with RA's Research Director. Supervisors need a
46 clear point of reference if they need advice and this should be built into any mentoring
47 scheme.
48

49 50 *Matching mentors with mentees*

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53 Mentees needed to be made aware that, although they could specify the sort of mentor
54 they would like, it might not be possible to find 'their' perfect mentor -and in some
55 instances their preferred choice might be deemed unhelpful, emphasising the individual
56 nature of the programme. In general personal choice was met wherever possible although
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3 the limited age range of available mentors meant that it was not possible to find mentors in
4 the preferred age range. The overall limited number of male mentors recruited was also an
5 issue. Concerns were raised about boundaries and expectations. For example one male
6 mentee particularly wanted a young female mentor, which in his case was deemed
7 inappropriate for the reasons given for the request. Issues also arose around
8 communication, understanding, expectations and identity when matching a mentee with a
9 mentor on the autism spectrum. One mentee commented:
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13
14 *“Having a mentor on the spectrum has actually made me more insecure because whereas*
15 *I thought I would be able to draw similarities between myself and the mentor, she seems a*
16 *lot less far on the spectrum than me.”*
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18

19 This example highlights the requirement for a particular type of supervision, sensitive to
20 ‘autistic thinking and anxieties’ if both mentor and mentee are on the spectrum. It is
21 important to note that the literature includes many examples of mentoring between people
22 on the spectrum, which exists outside formal arrangements, and on the face of it operate
23 successfully.
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26
27 It was important to build in the opportunity to change mentors and whilst the reasons for
28 this are perhaps obvious, they did cause mentees feelings of anxiety. With hindsight, the
29 ramifications should have been clearer and this was an important learning point for future
30 schemes. The specificity of the project required mentees to set goals early and some had
31 difficulty in understanding the concept of ‘life goals’. In a practical mentoring scheme more
32 time could be allocated to making this idea clearer.
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36 37 *Type of mentoring*

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39 The mode of mentoring was the choice of the mentee but we found that some mentees had
40 technical difficulty communicating via online messenger, and that maintaining boundaries
41 was more of a problem when mentoring took place via email. The duration of mentoring
42 was stressful for some mentees who found an hour too long. The opportunity to check in
43 more briefly could be looked at in further studies.
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47 48 *Administration*

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50 Funding did not allow for any administrative support for the project and fell to the research
51 team. This placed additional demands and should be factored in to replication.
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54 55 **Conclusion**

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3 Participants on the autistic spectrum reported their mentoring experience very helpful in
4 enabling them to progress toward self-identified goals, and mentees felt empowered by the
5 person-centred ethos and methods employed on the project. That said, mentoring is a
6 serious and far-reaching intervention with potential positive and adverse consequences
7 (Western, 2012). If done well it is a promising and useful addition to the range of helpful
8 approaches. Done badly it has the capacity to cause harm.
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11
12 A number of aspects of the mentoring project have been identified for requiring further
13 investigation, including: Training course duration, expectations and boundary setting,
14 supervision, flexibility, and the matching of mentees with mentors. Personal construct
15 theory (Kelly, 1955; Salmon, 2003) provided a sound framework in training for emphasising
16 the role of the mentor in facilitating the mentee in setting and working towards their goals
17 (set by mentees and facilitated by mentors when needed). In order to build on the pilot with
18 a view to operationalising a mentor scheme that includes the essential components
19 identified here, a larger scale research project would be needed.
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25 The project has highlighted the potential benefits of time-limited goal-orientated mentoring
26 with adults on the autism spectrum. The research team would urge great caution and
27 conclude that based on our experience of this project and the absence of an established
28 evidence base, to offer mentoring to this group outside of a formal supervised structure
29 without training and support is potentially reckless and risks harm.
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33 The current situation on mentoring appears at best patchy with the terms mentoring and
34 befriending often conflated. Inadequate supervision of mentors is also a particular concern,
35 as is the lack of clarity about boundaries around mentoring support. Training does not
36 currently appear to be a requirement for mentoring arrangements, and where it is offered
37 the essential safeguards are not universally included. Additionally, the content and delivery
38 is not necessarily informed sufficiently by the engagement and perspectives of autistic
39 people. In order for the project to realise its emancipatory aim (Barnes and Sheldon, 2007)
40 of ultimately producing an intervention informed by, and practically useful to autistic
41 people, the research team would suggest further research in this area is needed to
42 investigate these factors.
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48 The results of this pilot study clearly indicate that mentoring has value for adults on the
49 autism spectrum, and this preliminary evidence can be used as the basis for launching a
50 further trial, including a health economics perspective, to further inform recommendations
51 for mentoring as an effective intervention in improving mental wellbeing, and supporting
52 better life outcomes for people on the autism spectrum.
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56 57 Acknowledgements

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8 **References**

9

10 Autism in Pink, Retrieved 01/07/16; available at: <http://autisminpink.net/>
11

12
13 Barnes, C. and Sheldon, A. (2007) 'Emancipatory' disability research and special educational
14 needs in L Florian (ed) *Handbook of Special Educational Needs*. London: Sage.
15

16
17 Braun, V. and Clarke, V. (2006) Using thematic analysis in Psychology, *Qualitative Research*
18 *in Psychology*, Vol. 3: 77-101.
19

20
21 Brugha, T., McManus, S., Bankart, J., Scott, F., Purdon, S., Smith, J., Bebbington, P., Jenkins,
22 R., and Meltzer, H. (2011) Epidemiology of Autism Spectrum Disorders in Adults in the
23 Community in England. *Arch Gen Psychiatry*, Vol. 68(5): 459-465.
24
25

26
27 Fabri, M., Andrews, P. and Pukki, H. (2016) Using design thinking to engage autistic
28 students in participatory design of an online toolkit to help with transition into higher
29 education, *Journal of Assistive Technologies*, Vol. 10(2): 102-114.
30
31

32
33 Gelbar, N. Smith, I. and Reichow, B. (2014) Systematic review of articles describing
34 experience and supports of individuals with autism enrolled in College and University
35 Programs, *Journal of Autism and Developmental Disorders*. Published online: 11/05/14.
36
37

38
39 Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., and Bölte, S.
40 (2016) Premature mortality in autism spectrum disorder, *The British Journal of Psychiatry*,
41 Vol. 208(3): 232-238.
42

43
44 International Wellbeing Group (2006) *Personal Wellbeing Index*. Melbourne: Australian
45 Centre on Quality of Life, Deakin University.
46

47
48 Kelly, G. A. (1955) *The Psychology of Personal Constructs Volume 1: A Theory of Personality;*
49 *Volume 2: Clinical Diagnosis and Psychotherapy*. New York, US: Norton.
50

51
52 Mentoring and Befriending Foundation (2017) *What is Mentoring?* Retrieved 26/04/17;
53 available at: [http://www.mandbf.org/wp-content/uploads/2013/07/What-is-mentoring-](http://www.mandbf.org/wp-content/uploads/2013/07/What-is-mentoring-and-befriending-5.8.14.pdf)
54 [and-befriending-5.8.14.pdf](http://www.mandbf.org/wp-content/uploads/2013/07/What-is-mentoring-and-befriending-5.8.14.pdf)
55
56
57
58
59
60

1
2
3 Milton, D. (2014) Autistic expertise: a critical reflection on the production of knowledge in
4 autism studies. *Autism: The International Journal of Research and Practice* (special edition
5 'Autism and Society'), Vol. 18(7): 794-802.
6
7

8 Milton, D. and Sims, T. (2016) How is a sense of well-being and belonging constructed in the
9 accounts of autistic adults? *Disability and Society*, Vol. 31(4): 520-534.
10

11 Milton, D., Sims, T., Dawkins, G., Martin, N. and Mills, R. (2017) The development and
12 evaluation of a mentor training programme for those working with autistic adults, *Good
13 Autism Practice*, Vol. 18(1): 25-33.
14
15

16 National Audit Office (2009) *Supporting People with Autism through Adulthood*. Retrieved
17 14/10/16; available at: <http://www.nao.org.uk/wp-content/uploads/2009/06/0809556.pdf>
18
19

20 National Autistic Society (2017) *Autism*. Retrieved 10/05/17; available at:
21 <http://www.autism.org.uk/about/what-is/asd.aspx>
22
23

24 Pelton, M. and Cassidy, S. (2017) Are autistic traits associated with suicidality? A test of the
25 interpersonal-psychological theory of suicide in a non-clinical young adult sample, *Autism
26 Research*. doi:10.1002/aur.1828 [online],
27 <http://onlinelibrary.wiley.com/doi/10.1002/aur.1828/abstract> , accessed 08/07/17.
28
29

30 Povey, C. (2015) What should services for people with autism look like?, *Advances in
31 Autism*, Vol. 1(1): 41-46.
32
33

34 Salmon, P. (2003) A Psychology for Teachers. In F. Fransella (Ed) *International Handbook of
35 Personal Construct Psychology*, Chichester: Wiley.
36
37

38 Sasson, N., Faso, D., Nugent, J., Lovell, S., Kennedy, D., & Grossman, B. (2017) Neurotypical
39 peers are less willing to interact with those with autism based on thin slice judgments.
40 *Scientific Reports*, Vol. 7(40700). doi:10.1038/srep40700 [online],
41 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5286449/>
42
43
44

45 Sheppard, E., Pillai, D., Genevieve, T., Ropar, D., and Mitchell, P. (2016) How Easy is it to
46 Read the Minds of People with Autism Spectrum Disorder? *Journal of Autism and
47 Developmental Disorders*, Vol. 46(4): 1247-1254.
48
49

50 Western, S. (2012) *Coaching and Mentoring: A Critical Text*. London, UK: Sage.
51
52

53 Related publications:
54
55
56
57
58
59
60

1
2
3 Milton, D., Sims, T., Dawkins, G., Martin, N. and Mills, R. (2017) The development and
4 evaluation of a mentor training programme for those working with autistic adults, *Good*
5 *Autism Practice*, Vol. 18(1): 25-33.
6
7

8
9 Ridout, S. and Edmondson, M. (2017) Cygnet Mentoring Project: combined experiences
10 from a mentor and a mentee, *Autonomy: the Critical Journal of Interdisciplinary Autism*
11 *Studies*. Vol. 1(5), [online], [http://www.larry-](http://www.larry-arnold.net/Autonomy/index.php/autonomy/article/view/AR20/html)
12 [arnold.net/Autonomy/index.php/autonomy/article/view/AR20/html](http://www.larry-arnold.net/Autonomy/index.php/autonomy/article/view/AR20/html)
13

14
15 Sims, T., Milton, D., Martin, N. and Dawkins, G. (2016) Developing a user-informed training
16 package for a mentoring programme for people on the autism spectrum. *The Journal of*
17 *Inclusive Practice in Further and Higher Education*, Vol. 6: 49-52.
18
19

20
21 Mills, R and Milton, D (2015) If it's good enough for Cherie Blair...The Cygnet life-coaching
22 and mentoring programme for adults with autism. *Share Blog*, Winter 2015, Accessed:
23 [http://www.scottishautism.org/about-autism/centre-for-practice-innovation/share-blog-](http://www.scottishautism.org/about-autism/centre-for-practice-innovation/share-blog-issue-2/cygnet-life-coaching-mentoring/)
24 [issue-2/cygnet-life-coaching-mentoring/](http://www.scottishautism.org/about-autism/centre-for-practice-innovation/share-blog-issue-2/cygnet-life-coaching-mentoring/)
25

26
27 Milton, D. and Sims, T. (2014) A review of mentoring guidance for students on the autism
28 spectrum. In B. Morris, T. Perry, and M. Hand (Eds) *Papers from the Education Doctoral*
29 *Research Conference, Saturday 29th November 2014*. Birmingham: University of Birmingham,
30 pp. 124-130.
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
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