Considering employment of young people with intellectual impairment and autism leaving school and college [chapter head]

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Abstract [A head]

This article begins by exploring relevant UK legislation and government initiatives designed to support transition to work for young disabled people, and reflects upon their relevance, specifically for autistic individuals with additional intellectual impairments. Research from within and beyond the UK has painted a positive picture of the benefit of employment to the employee and the workplace, whilst noting that systems to support and encourage engagement with work are somewhat patchy and often underdeveloped. At the time of writing, just after the 2017 general election, the future seems rather uncertain.

The series of illustrative vignettes in the second part of this paper have been created to illustrate some of the strengths autistic people might bring to work, along with some of the barriers which may need to be addressed in order to help individuals to flourish. We conclude with a few practical recommendations. The systematic provision of opportunities to try out real-life work situations in order to make informed choices is highly recommended, particularly for people who find it hard to imagine situations they have not experienced before. Job trials are likely to be preferable to interviews and adequately trained and supervised work place mentors may well have a role to play. Ensuring that people who find it difficult to communicate verbally are enabled to make their ideas known is identified as an important consideration. Obviously clear, transparent and easy access to systems like 'Access to Work' would be helpful.

Introduction and scope [A head]

The aim of this article is to stimulate discussion about practical ways in which employers and practitioners from various disciplines might help young autistic people (who also have intellectual impairments) to transition from education to employment, and to flourish in the workplace. Austerity concerns and interactions between the benefits system and employment of disabled people fall outside the scope of this paper. At the time of writing the 2017 UK general election has just occurred and resulted in a (minority) Conservative government. We think it's fair to say that the future is uncertain. Documenting historic concerns is probably pointless as this paper is looking forward to consider practical ways in which work could be made more accessible to young autistic people with intellectual impairments. Barnham (2016) reflects on the disability employment gap, and the initiatives of the previous Conservative (majority) government, which arguably had little positive employment impact for the group with which we are concerned. This paper is

not looking outside the UK particularly, but it is interesting that scholars such as Hedley *et al* (2016) and Wehman *et al* (2016; 2017) paint a similar picture in their studies focusing on Australia and America. These studies illustrated both the value of employment and the lack of systematic support for securing and maintaining a job. It is possible that we will now be looking in the UK towards a new set of interventions and we live in hope that these are to be practical, beneficial and informed by the ideas and concerns of autistic people.

The Autism Act was first published in 2009 and subsequent revision to the original and to the Adult Autism Strategy (Department of Health, 2015) (for which the most recent statutory guidance was published 2015) have been reviewed by Parkin (2016). Working in tandem with The Equality Act (2010) the emphasis is placed on the requirement to raise awareness of what autism is and ways in which public services could systematically reduce access barriers commonly experienced by autistic people. Gainful employment is highlighted as an important facet of social inclusion, and autistic people (including those with intellectual impairments) have much to offer as employees. Arguably awareness raising and training of employers and service providers is most authentic when delivered by people with lived experience of autism.

Previous initiatives [A head]

Some historic attempts to address the under employment of disabled people in general, and autistic people in particular, have a degree of relevance to our discussion. Information is included in the next section to provide some context, which may stimulate thinking about what might be usefully developed and taken forward. Research Autism (http://www.researchautism.net/autism-publications/literature-reviews-autism/vocational-reviews-autism) provides a list of some useful autism focused articles.

16-25 education [B head]

The Children and Families Act (CFA) (2014) requires colleges and other post-16 providers to offer students study programmes which are coherent, appropriately challenging, and designed to support progression to apprenticeship or employment. This requirement covers 16-25 year olds where they have either a statement of special educational needs (SEND) or an education and health care plan (EHCP). Students with autism and intellectual impairment within this age range would fall under this umbrella and none of the political manifestos recently published suggest radical reforms of the CFA. Further education (FE) is not currently faring well in funding terms. In FE, vocational learning aims to include relevant work experience and learning support funding helps providers support learners with learning difficulties and disabilities by meeting the costs of reasonable adjustments, as set out in the Equality Act (2010). Many disabled students receive information, advice and guidance on employment/career choice, writing a CV and

volunteering opportunities. Some have access to work focussed coaches and mentors, but these schemes are few and far between and often fall short of the ideal standard of mentor training and supervision (Milton et al, 2017). A systematic review conducted by Gibson et al (2017) highlighted the obvious importance of hands on systematic high quality well organised work experience for students with intellectual impairments transitioning from education to employment.

Current initiatives [A head]

Current study programmes with a strong employment focus include the following. The relevant websites for these can be found in the Resources at the end of the chapter.

Supported internships [B head]

These are unpaid, structured study programmes, based primarily with employers, which aim to help young people aged 16-24 (who have EHC plans or statements of SEN) to achieve sustainable paid employment through developing the skills they need for work by learning these skills in the workplace. For autistic learners, developing skills in context has potential advantages, or at least may reduce the requirement to generalise from simulated classroom-based learning into the real workplace. Supported internships were trialed in 2012/13 in 15 FE colleges. Evaluation published in December 2013 found that 36 percent resulted in paid employment (Department for Education, 2013). The unpaid nature of these initiatives is obviously a cause for some equity concerns.

Traineeships [B head]

These aim to help young people who want to get an apprenticeship or job but do not yet have appropriate skills or experience. Traineeships are based on a mainstream education and training programme, with work experience focused on the sort of skills and experience that employers seek. At the core is work preparation training, English and maths for those that need it, and a high quality work placement. Where the emphasis is placed on English and maths mastery potentially a barrier can arise for some people aspiring to a trianeeship.

Apprenticeships [B head]

These were described as a priority for Theresa May's majority government which introduced the 'apprenticeship levy' (HM Revenue & Customs, 2016). They are designed to allow young people or adult learners to earn while they learn in a real job, whilst also gaining a qualification. May's pre-June 2017 government showed signs of commitment to making apprenticeships inclusive and accessible and incentivising employers to embrace the idea of offering them. An understanding of the requirements of potential apprentices who have autism and intellectual impairment would clearly be essential in order for this group to benefit and for employers to make the most of the potential value those with the skill sets often associated with autism might bring to work. Where maths and English qualification requirements are stipulated further obstacles can occur.

A number of labour market programmes presently exist to offer help to people with learning difficulties and disabilities, including:

Work Choice [B head]

This is a voluntary programme which is described as offering disabled people a range of help to find, get and thrive in a job. Over a quarter of Work Choice referrals (27 percent) have learning disability recorded as their primary impairment.

Access to Work [B head]

Access to Work provides grants to cover additional costs of starting or staying in work (including traineeships and supported internships). This can include specialist equipment, transport costs, support or workplace job coaching and disability awareness training for colleagues. 36,470 people used Access to Work in 2015/16 (Department for Work & Pensions, 2016). The need for job coaches to understand, without stereotyping, the sort of challenges and strengths someone with autism and intellectual impairment might bring, has already been stated. Disability awareness training reflecting the voices of autistic people would be ideal.

Disability Employment Advisers [B head]

The Department for Work & Pensions has a network of around 400 Disability Employment Advisers in Job Centres. Part of their remit is to understand the various initiatives described here, including Access to Work. Autistic people could usefully find employment delivering their training.

Disability Confident campaign [B head]

This campaign is an initiative through which May's last government worked with employers with the aim of helping them feel more confident about employing disabled people through signposting available support and showcasing success stories. While 79 per cent of employers said they 'would consider in principle' employing disabled people, only 22 per cent had in the preceding 12 months. The gap between disabled and non-disabled employment rates varies widely by locality. A 2012 survey found that across the UK it was then 38 percent. In Cumbria it was 48 percent, while in Hertfordshire it was 25 percent (Office for National Statistics, 2012). Figures tended not to isolate information about people with autism and intellectual impairment so are of limited value to our discussion here. Success stories delivered by autistic people would help employers to see the benefits of creating work environments to support maximising the strengths of autistic workers.

Barriers to autistic young people with additional intellectual impairments entering and sustaining employment [A head]

This section discusses issues which focus more specifically on 'the group' under consideration (whilst always acknowledging the individuality of every person). Lack of flexibility in education may lead some learners to drop out or to leave education without the sort of qualifications which mean something to employers. This is particularly so for special school pupils who may not necessarily have access to qualifications they are capable of gaining. Douglas et al (2016) Potential obstacles relating to maths and English qualifications have already been discussed in relation to apprenticships and traineeships.

Disabled people may be reluctant to disclose to potential employers, fearing their abilities may be doubted before they get chance to demonstrate what they can do. Autistic people live with negative stereotypes, such as from the film *Rain Man* and this may well impact on decisions around 'disclosure' (which is, in itself, like 'disorder', a problematic D word).

Employers may look at what they perceive that a young disabled person *can't* do, rather than what they *can* do. When an individual with autism and intellectual impairment does not use their voice to communicate, the employer might make assumptions about their capabilities which are misjudged. Advocacy and self-advocacy may be required in order for this barrier to be addressed. In the case of advocacy, it is important that the advocate is on the same page as their 'client' and has achieved this by going to great lengths to find out what it is that the young person aspires to. Self-advocacy is only possible if the individual has been able to develop or has been equipped with a means of communication and has had access to a range of experiences which would enable them to make realistic choices. Mentoring under these circumstances is a highly skilled process requiring subtle, focused training and ongoing supervision.

Limited awareness amongst professionals of what support services are available for disabled young people create further blocks in the road to work. The elephant-sized roadblock is the lack of opportunities which are autism focused, autism informed and of high quality. Excellent opportunities for young people with autism and intellectual impairments are uncommon in the workplace, and poorly organized transitions can disrupt effective support.

There may be some system issues to consider. The Children and Families Act (2014) was underpinned by a philosophy of joined up thinking but it is not clear whether the responsibilities of schools, colleges, local authorities and government agencies are clear and complementary in relation to progression into work. Effective transitions for individuals need to be seamlessly supported, as change is already known to be challenging for autistic people, without introducing elements of avoidable chaos at a systems level. It is necessary to consider ways in which the process of assessment and securing

support could be simplified, and made more 'transition-proof' as people move from education into work.

It is important to ascertain whether there is a consistent approach across government and sector. With a reliance on local authorities in the school vears and individual institutions and providers of FE, and a range of initiatives (examples of which were provided earlier) to support progression to work, the sense of there being a joined up approach is tenuous. The extent to which information, advice and guidance is autism aware, autism informed, readily available to autistic people, and able to support autistic people (including those with intellectual impairments) in tackling barriers to work, is unquantified. Although the Equality Act (2010) exists and the Children and Families Act is specifically targeted at smoothing the 16-24 transition, there isn't a clear sense of a national picture around good practice in, for example, disclosing to employers, seeking reasonable adjustments and accessing support such as Access to Work. The Autism Act (2009) and subsequent Adult Autism Strategy (Department of Health, 2015) were designed to improve 'the local offer' and to up-skill the workforce of public servants who may impact on the lives of autistic people, but this has not translated into an army of autism-aware people willing and able to help their autistic clients to find and keep a job. Company human resource departments may well be on the frontline when it comes to the employability equality agenda but there is scant evidence of autism-focused, autism-informed training to help personnel in these roles to be effective.

Possible solutions – first thoughts [A head]

Barnham's 2016 report posed some questions which related to the wider community of potential disabled employees but also resonate here. The report was written prior to the 2017 general election being called and this paper has been authored while the minority Conservative government is still settling. We live in hope that, whichever party is in power in the future, autistic voices will influence the trajectory of any reforms and that these will be sensible and adequately resourced.

Barnham (2016) proposed that in view of the focus on 0-25 in special educational needs and disability, further education and employers may be best placed to work with the grain of that change toward employment outcomes. For those who use means other than verbal language as their main mode of communication, there may be mileage in some kind of 'passport', which could outline strengths and support requirements to ease the transition to work. Case studies from employers could possibly be used to develop a 'transition toolkit' and training materials aimed at potential employers and gatekeepers to employment (such as job centre staff).

Autism and intellectual impairment focus: hypothetical case studies and discussion [A head]

Mentoring [B head]

The Research Autism Cygnet Mentoring project based at London South Bank University (Milton *et al*, 2016) highlighted the benefits of goal orientated fixed term mentoring to enable autistic adults to identify and achieve their own goals, including goals around employment. While the focus of the project did not specifically encompass the requirements of people with autism and additional intellectual impairments, the lessons learned are pertinent. Issues of cognition and communication require careful consideration in relation, particularly, to addressing the requirements of people who may not communicate well verbally and may have difficulty with the concept of 'future self'. This idea was discussed fully by Sally Brett in the first volume of the annual and Sally's article merits a second read (Brett, 2016).

Mentoring people with autism and intellectual impairments towards thinking about employment requires the mentor to avoid a tokenistic and bossy engagement with the complex question of what an individual might like to do as a job in the future, particularly when ideas like 'job' and 'future' are not something which is easily comprehensible. Concepts which may seem quite abstract need to be made meaningful for an individual via the provision of opportunities for lived experience. Saying 'would you like to work in horticulture?' within a sterile indoor environment will certainly make far less sense to someone who does not know what 'working in horticulture' involves, than would the opportunity to get their hands dirty in the act of planting seeds or bedding plants.

The Cygnet project used fictional vignettes to illustrate the sort of mentoring which may be effective in the workplace and these were incorporated into mentor training. Autistic voices were prominent in all mentor training sessions and this was commented on by participants as a real strength. For Cygnet, resources like the channel silentmiaow on YouTube (https://www.youtube.com/user/silentmiaow) (an autoethnographic account by an autistic person who does not communicate verbally but can explain her motivation using technology) helped with understanding nonverbal engagement with the world.

Further mentor training is being developed to specifically address the requirements of people who possibly have less understanding of employment or less capacity to express themselves conventionally with words than that of the Cygnet participants. This training will incorporate the concept of future self and the requirement to experience, in real life, what a job might be like, rather than to discuss it in an abstract context, even if this is with the aid of some form of visual prompt. A picture of a flowerpot does not convey the smell of compost.

Mentoring involves listening and helping the mentee to identify and work towards their own goals. When words are not the primary mode of communication, and concepts cannot be grasped easily in the abstract, the task of mentoring has to be approached differently. A more nuanced engagement is necessary to present ideas in a way which the mentee will understand, often through access to real experience, and to ascertain the meaning the mentee is making of them. Listening can become watching the reaction of an individual within real contexts, which can convey more meaning than would be possible by looking at a two dimensional image. In an attempt

to get this idea across in training, the following fictional stories have been devised.

Illustrative vignettes [A head]

Anna [B head]

Anna attends a special school. She is seventeen years old, communicates with the aid of visual supports (pictures) and can make choices between two pictures or two objects, with understanding. She has strong likes and dislikes and it is easy enough for people who know Anna to work out what these are because her nonverbal communication is effective. Her preference is to be outside. Anna's school is organizing work experience and this has been discussed with her, using picture aids. When given a picture of a car and a picture of a greenhouse and asked 'which one do you like', she pointed to the greenhouse. The work experience will be in a garden centre greenhouse. Anna will be supported by a teaching assistant and will plant bedding plants for two hours a day over a one week period. When Anna gets to the garden centre she is distressed as she does not like the feel of the soil on her hands. The work placement is not a success.

Anna really likes being in the park. At eighteen years old she spent three hours a day, two days a week over four weeks with her teaching assistant and a park worker, and was able to see and try out various tasks including planting, sweeping and picking up litter. Anna indicated a preference for picking up litter and had a very successful work experience in the park after it had been established that she would be litter picking.

After Anna left school at nineteen years old she was supported in developing a portfolio of activities including continuing her education at a further education college and focusing on independent living and employability skills. By twenty-one Anna was living in supported accommodation with two other young women and with some support was working two days a week picking up litter and working in the greenhouse in the park. On two further days each week she was accessing the community with assistance. This included going to the cinema on a Tuesday afternoon. Anna was able to communicate her choices and had a weekly timetable with pictures and symbols to help her to make sense of her activities. As she is not yet twenty-five, her Education and Health Care Plan still operates as a coordinating document between the various agencies working together to help Anna to reach her potential.

The three examples below from The Cygnet Project mentor training (Milton *et al*, 2017) further illustrate some of the sorts of issues which might arise at work and the requirement for sensitivity and clarity on the part of the mentor.

Ali [B head]

Ali is a very hard worker who loves everything to do with gardening. He does not mind the weather, is always punctual and extremely reliable. When he is given detailed instructions, sometimes with a sequence of pictures to help him if a task is unfamiliar, he just gets on with it. Recently he has been

exploited by a peer who has passed his work onto Ali and sat in the shed on his phone. Ali does not realise that his mate is exploiting his good nature. This situation will not change unless someone very sensitive intervenes in a way which does not ruin Ali's enjoyment of his job.

Jean [B head]

Jean is reliable, serious, hardworking and productive. She has recently started a clerical job in an open plan office which is hot, noisy, crowded and has strip lighting. Her bus was late, she stood up all the way and arrived late. Her supervisor said 'what time do you call this'. Jean looked flustered and the supervisor said 'never mind, just finish that stuff off from Friday, chop chop'. Jean went to the toilet and locked herself in. Fifteen minutes later she was still there.

Jean is still in the toilet after half an hour. She is sitting on the floor, feeling hot, anxious and frightened. She is very quiet and preoccupied and is not sure how to get herself out of the situation. Her supervisor is asking office staff where she is. Jean can hear him. Jean's workplace mentor arrives and is told what is going on by the supervisor. The mentor takes it from there.

Simon[B head]

Simon attends an FE college and his course includes a work placement one day a week as a car valet. He has been coached into the role by a volunteer job coach, Abdul, who works at the car valeting workshop full time. Abdul was supported to understand Simon's requirements in order to assist him effectively. Simon does not use speech and a communication passport was developed as the main tool to initially get across Simon's likes, dislikes, strengths and general way of operating. He is good at imitating and Abdul is good at demonstrating. In the first few weeks Abdul would demonstrate a task, such as polishing, and Simon would copy. The order of tasks was always logical and sequential. By week 5 Abdul and Simon worked side-by-side on separate cars. Abdul keeps an eye on Simon and both of them enjoy the experience of working together. Abdul has access to a supervisor from the college in case he has any questions and Simon's work experience is also monitored by college staff.

Practical considerations [A head]

Work experience is important. It is particularly difficult for someone on the spectrum to imagine a situation which they have not experienced, therefore exposure to job taster opportunities is essential in order to facilitate informed choice. In the case study utilised as an example here, Simon very much enjoys his work experience in the car valeting shop.

Work trials with support are more appropriate than conventional interviews. Ali, for example, could shine in the greenhouse because of his enthusiasm for horticulture, but does not have the communications skills to get this across verbally. Anna didn't actually like planting things when she got to experience this in real life.

A work-placed mentor who understands the requirements of the individual would be helpful, at least initially, and on an ongoing basis as someone to turn to if difficulties arise. The requirements of the job role need to be explicitly communicated in ways which meet the requirements of the individual. Visual timetables, picture prompts and assistive technology have been discussed in the first volume of this series and are equally relevant at work. Help to navigate the social and sensory world of work will also be important. Jean is clearly finding the sensory environment of her office horrible. Anna had sensory issues with the feel of wet soil.

The chapter on Universal Design in the first volume (Milton *et al*, 2016) discusses strategies which would work in employment. The REAL model (Hastwell *et al*, 2013) for example, emphasises the requirement for reliability, clarity, anticipation (in order to avoid potential difficulties) and logical clear communication is readily applicable to work. Unclear communication is also having a negative impact on Jean. Anna could not make any sort of decision about the sort of work she might like when shown a picture of a car and a picture of a greenhouse. It is quite a big cognitive leap to make assumptions from these images to the real working world of horticulture or car maintenance.

Full or part time or voluntary employment can have a positive impact on well-being and self-esteem. Work which relates to the interests of the individual will be most rewarding. Simon loves cleaning cars and he is good at it. It is necessary to be imaginative about the sort of occupation that might be feasible with a little support, and to find ways of accessing an understanding of what the individual might like to do, especially if their mode of communication is unconventional. Observing that someone is happiest outside, for example, might lead down the path of looking at the feasibility of some sort of outdoor work. Anna's work involves being outside, which she likes, and is part of a portfolio of coordinated and fulfilling activities which make up a full and active timetable.

Background has been provided on funding streams such as Access to Work but there is evidence that these sources of support are poorly understood (Milton *et al*, 2017). The role of work-based volunteers also merits consideration, with caution. As with mentoring relationships, boundaries have to be clear, and supervision is important. Abdul is gaining a lot from his role in supporting Simon at work. He received adequate training to fulfil the role and knows that he has access to a supervisor. The sustainability of the arrangement merits discussion. Simon is on a college-based work placement but he is capable of making an ongoing contribution to the workplace with the right sort of support.

Conclusion [A head]

In a time of huge political uncertainty this paper has explored some of the issues which surround the idea of employment of autistic people with intellectual impairments. In an ideal world, gatekeepers would be committed

to the idea and would know exactly what they are doing, having been trained by autistic people to understand the strengths and aspirations of autistic people, including those with intellectual impairments who do not use verbal language to communicate. In an ideal world work place mentors would be trained by autistic people and mentoring schemes would all be safely supervised. In an ideal world employers would welcome autistic people with intellectual impairments with open arms. In an ideal world joined up, adequately resourced, carefully monitored systems would smooth transitions and provide safe ongoing support to enable people with autism and intellectual impairments to flourish, not only in work, but in all aspects of their lives.

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Resources – initiatives [B head]

(accessed September 2017).

- Supported internships www.preparingforadulthood.org.uk/what-we-do/supported-internships
- Traineeships <u>https://www.gov.uk/find-traineeship</u>
- Apprenticeships

https://www.gov.uk/government/publications/help-and-support-for-young-disabled-people-to-find-and-stay-in-work (guidance updated 27-06-17).

- Work Choice https://www.gov.uk/work-choice/overview
- Access to Work https://www.gov.uk/access-to-work/overview
- Disability Employment Advisers <u>www.jobcentreguide.co.uk/jobcentre-plus-guide/34/disability-employment-advisors</u>
- Disability Confident campaign https://www.gov.uk/government/collections/disability-confident-campaign