Research Project Report
(C85RES)

University of Lincoln

Doctorate in Clinical Psychology

2013

**Autism and Transition to Work: A Thematic Analysis of
Service User Experiences**

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Submitted in part fulfilment of the requirements for the

Doctorate in Clinical Psychology

Acknowledgements

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Autism and Transition to Work: A Thematic Analysis of Service User Experiences

1. Abstract

Introduction

This study investigates the experiences of individuals with autism spectrum conditions (ASC) as they experienced transition into employment in the UK. The high prevalence of ASC has led to increased social and economic pressures (Gerhardt & Lainer, 2010), with the estimated yearly cost to the UK for each individual at £90,000 (Knapp, Romeo & Beecham, 2007). Employment may help to reduce economic pressures, benefit individuals and society (Howlin, Alcock & Burkin, 2005). Individual gains in cognitive functioning (García-Villamisar & Hughes, 2007), quality of life and self-esteem (Eggleton et al., 1999) may be experienced. However, individuals with ASC tend to find transitioning to employment difficult, due to implicit characteristics associated with the condition (Berney, 2004). Transitions represent challenges to individuals' social identity and self-concept, require behaviour change and may contribute to distress (Liddle, Carlson & McKenna, 2004). These factors may be exacerbated in individuals with ASC due to their difficulties with social and behaviour change processes (American Psychiatric Association [APA], 2010).

Transition and employment support strategies have been shown to facilitate successful employment for individuals with ASC (Howlin et al., 2005). The National Institute for Health and Clinical Excellence ([NICE], 2012) propose how best to support people with ASC, based on the synthesis of available evidence. However, the evidence lacks in consideration of individuals' experiences and psychological theories of support and transition. Considering these perspectives may facilitate service users to influence effective service provision, through disseminating their views and experiences of transition to work by means of a rigorous qualitative study.

Method

This study investigates the experiences of 10 participants with ASC during their transition to employment settings in the UK and aims to provide them with a platform to express their experiences and views of this process. An inductive thematic analysis methodology (Braun & Clarke, 2006) is used to explore semantic information obtained from retrospective interviews relating to the experiences of transition to work and identify frequent and salient themes within the data (Buetow, 2010).

Results

Analysis identified three main themes that were particularly salient and frequent for the interviewed participants:

> ***Diagnosis**; comprised of subthemes 'Access to support', 'Identifying with ASC', 'Other-understanding' and 'Delay in diagnosis'.*

> ***Barriers to transition**; comprised of 'Socio-economics', 'Physical accessibility' and 'ASC characteristics'.*

> ***Transition support**; comprised of 'Emotional needs', 'Clear guidance and honest feedback', 'Practical support' and 'Social integration'.*

Discussion

Thematic analysis facilitated investigation into the experiences of 10 participants with ASC as they transitioned to work. Participants' difficulties and needs were reflected in the existing evidence base and aims of current legislation and guidance, but short-comings in the delivery of these were also highlighted. In addition, a unique insight into both the positive and negative emotional impact of transition to work for individuals with ASC was obtained. Psychological models of support and transition are considered in relation to the experiences of transition and associated challenges to self-concept. Potential support measures for more effective and less distressing transition to work are discussed.

2. Statement of Contribution

Tom Brockwell was responsible for the design of this research project, applying for and obtaining ethical approval, reviewing the relevant literature, the recruiting of participants, data collection, data analysis and write up of the project.

Dr. Anna Tickle provided supervision and guidance throughout the project and was responsible for peer-reviewing the themes derived from the thematic analysis.

Craig Sutherland supported the recruitment of participants.

3. Part I. Journal Paper

Autism and supported transition to work: A thematic analysis of service user experiences[1][2]

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3.1. Abstract

This study examined the experiences of 10 adults with Autism Spectrum Conditions (ASC) as they transitioned to employment settings in the UK. An inductive thematic analysis of interview transcripts identified three themes that were particularly salient and frequent for the participants: '*Diagnosis*' comprised of the sub-themes *Access to support, Identifying with ASC, Other-understanding* and *Delay in diagnosis*. '*Barriers to transition*' contained sub-themes of *Socio-economics, Physical accessibility* and *ASC characteristics. 'Transition support'* included *Emotional needs*, *Clear guidance and honest feedback*, *Practical support* and *Social integration*. This paper explicates '*Transition support*', which was felt to be the most relevant theme in the context of recent government legislation and guidance. Participant experiences of '*Transition support*' are discussed with reference to best-practise guidelines and in the context of psychological theories of support, transition and ASC. (For consideration of other themes, see extended paper, section 4).

Keywords. Autism, transition, employment, work, thematic analysis

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3.2. Introduction

Autism in the UK

Autism Spectrum Disorders (ASD) are developmental disorders characterised by the co-occurrence of two factors; 'social and communication deficits' and 'fixated interests and repetitive behaviours' (American Psychiatric Association [APA], 2010). Individuals with ASD may be affected to different extents on both factors, leading to the conceptualisation of 'autism' as a spectrum (Wing, 1997). Functionally, individuals may have impaired understanding and use of non-verbal behaviours, fail to develop appropriate peer relationships and lack social or emotional reciprocity (APA, 2000). These factors may negatively impact upon individuals' experience of their social environment (Hurlbutt & Chalmers, 2002), contributing to decreased quality of life and increased mental health difficulties (Jennes-Coussens, Magill-Evans & Koning, 2006).

Many individuals with ASD oppose the view of autism as a disorder and view it as a neurological difference from the 'neuro-typical' population, therefore preferring the terminology of 'Autism Spectrum Condition' (ASC) (National Institute for Health and Clinical Excellence [NICE], 2012). As such, the terms ASC and autism will be used interchangeably in this paper to represent all disorders on this spectrum.

Research into prevalence rates of ASC has led to speculation of an 'autism epidemic' (Wazana et al., 2007). However, rates are unlikely to be increasing in real terms, rather that ASC is perceived to be becoming more common as a result of increased awareness and broadening diagnostic criteria (Brugha et al., 2011).

Prevalence rates are now consistently reported to be about 1% across child and adult populations (NICE, 2012).

Knapp, Romeo and Beecham (2007) estimated the yearly cost to UK society for each adult with ASC to be £90,000. Barnard et al. (2001) estimate that 32,000 of these could be supported into employment, saving the government a projected £25 billion. Additionally, individual benefits of employment include improved cognitive functioning (García-Villamisar and Hughes, 2007), quality of life and self-esteem (Eggleton et al., 1999).

Recently in the UK, ASC diagnosis and management has come to the forefront of political and public arenas. The Autism Act (2009) and Autism Strategy (Department of Health [DoH], 2010) have been instrumental in promoting the rights of people with ASC to have access to quality support and services appropriate to their needs. The Autism Strategy (DoH, 2010, p.4) states that one of its main objectives is "looking directly at the challenges faced by adults with autism in getting into work and keeping a job, as part of our wider goal of achieving full employment".

Autism and employment

Evidence suggests that individuals with ASC often make very good employees, tending to be punctual, honest and loyal (Shepherd, 2004). Hillier et al., (2007) state that individuals with ASC can be successful in competitive employment and are frequently rated highly by employers on job skills. Despite this, they are at greater risk of unemployment and underemployment, compared to the general

population (Higgins et al., 2008). This is most likely due to impairments in communication and social functioning, rather than difficulties with the requirements of the role (Higgins et al., 2008; Hurlbutt and Chalmers, 2004). Howlin et al. (2004) surveyed UK adults with ASC and found only 13% to be competitively employed and 18% employed in a sheltered or supported setting. This discrepancy highlights the need for appropriate support to ensure individuals with ASC are provided equal opportunities for employment.

Supported transition to work

Supporting individuals with ASC into employment may be an effective means of increasing employment rates (Howlin et al., 2005) and improving quality of life (NICE, 2012). NICE (2012) guidelines recognise supported employment for people with an ASC as a cost effective intervention, at least equal, if not superior, to standard care, comprising of supported living and day service provision. NICE (2012) suggest support measures include; accurately assessing individuals' needs and skills and matching these to suitable jobs, providing access to job coaches and providing on-the-job supports. Most of the evidence cited by NICE (2012) relates to outcomes or questionnaire data and neglects the perspectives of individuals with ASC, although some case studies are reported (e.g. Hurlbutt and Chalmers, 2002).

The NICE (2012) guidelines do not appear to consider psychological theories of support or transition and how these might apply to individuals with ASC. This results in a lack of focus on individual experiences, person-centred principles and a tendency to refer to ASC in relation to a medical deficit model. No studies

appear to utilise a rigorous qualitative methodology to investigate the transition experiences of a UK sample of adults with ASC who have been supported into employment. This not only neglects an important source of information relating to individual experiences, it also deprives potential service users of a voice and influence over shaping their services.

Transition

Transition to work constitutes a significant challenge for individuals with autism. It represents a departure from known routines, requires generalisation of learning and invariably involves social reciprocity (Berney, 2004). These are all areas of potential difficulty for people with ASC, given the associated difficulties in rigid and repetitive behaviour and social communication (APA, 2010). Higgins et al. (2008) suggest that the aim of transition to work should be to successfully navigate these difficulties and assume employment, whilst minimising distress.

Transition has been defined as a "discontinuity in a person's life space" (Adams, Hayes and Hopson, 1976, p. 5) and is often associated with a change in life roles (Liddle, Carlson and McKenna, 2004). Events such as obtaining an ASC diagnosis, or the status of 'employed' create opportunity for changes in social group identity and self-concept to be experienced. Group identity could be defined as a network of people who co-produce similar discourses, activities and artefacts (Holland et al., 1998). Obtaining work in a context dominated by neuro-typical individuals may highlight 'in-group' and 'out-group' processes, whereby individuals evaluate social groups they do not identify with (out-groups) less favourably than those they do (in-groups) (Tajfel and Turner, 1986). Individuals with ASC may be

at increased risk of stigmatisation or victimisation, and view neuro-typical individuals sceptically, as a result of these processes. This may impact upon self-esteem, well-being, work behaviours and transition success.

Psychological models of transition emphasise the associated experiences of loss, stress and decreased self-esteem (Liddle, Carlson and McKenna, 2004). Nicholson (1990) views transition as a process, or cycle, involving four stages: 'Preparation' involves the development of expectations, motives and feelings; 'Encounter' relates to building confidence in coping and sense-making, leading to 'Adjustment', characterised by personal change, role development and relationship building, and finally 'Stabilisation' through commitment and effectiveness (Nicholson, 1990). Nicholson's (1990) model is a synthesis of previous transition models and, whilst inherently inflexible as a categorical model, it does provide a useful framework in this context. (For further discussion on transition, see extended paper, section 4.4.1.).

Individuals are more likely to experience transitions positively if they are anticipated, chosen (Blair, 2000) and intrinsically motivated (Gagne and Deci, 2005). Self-determination (Gagne and Deci, 2005) in this context helps to develop an internal locus of control and improve self-efficacy, with associated benefits in mental health (Bandura, 1997). This highlights the importance of individuals being informed, committed and more in control of their transition processes so as to improve outcomes (Ronka et al., 2003). No models of transition specifically relate to individuals with ASC, making it unclear whether they apply. Such a dearth of

evidence highlights the need for exploratory research to inform the understanding of transition in this population.

Support through transition

Social support is thought to 'buffer' psychological distress to stressful life events in the general population (Cohen and Hoberman, 1983). The function of support can be emotional, tangible, provide information and appraisal, or positive social interaction (Sherbourne and Stewart, 1991). The perception of receiving support is often as important as the support itself (Sherbourne and Stewart, 1991). The impact of social support on the quality of life and transition to work experiences of people with ASC has not been studied (Dalrymple and Ruble, 1996; Jennes-Coussens, Magill-Evans and Koning, 2006). However, the level of perceived social support is positively correlated with wellbeing among adults with ASC in general (Dalrymple and Ruble, 1996), suggesting that social support may be beneficial to individuals with ASC as they transition to work.

Based on their review of the literature of ASC and transition to adulthood, and in line with the 'Preparation' phase of transition (Nicholson, 1990), Hendricks and Wehman (2009) suggest that transition to employment support should start in schools and specifically target school leavers. McEachern and Kenny (2007) describe two programmes which they consider facilitate transition; both contain support on career exploration and job searching, addressing barriers to employment, selecting training and addressing transition challenges. Effective communication and information sharing between agencies is also important (Schall and McDonough, 2010). McEachern and Kenny's (2007) suggestions are

not specifically related to individuals with ASC, but their contribution to transition 'Preparation' (Nicholson, 1990) may indicate their utility in this context. Research investigating service user experiences of transition may clarify and identify ASC specific areas for intervention.

In line with the 'Encounter' phase of Nicholson's (1990) model of transition, individuals should be facilitated to learn and practice work behaviours and develop self-awareness of their personal strengths, weakness and interests (Higgins et al, 2008). Individuals should be supported to set skills-based, person-centred transition goals (Hendricks and Wehman, 2009), which address communication and social skills in multiple contexts (Schall and Wehman, 2008). Hendricks and Wehman (2009) state that transition services should be user led, career-focused and supported by employment specialists, who could act as advocates and 'job coaches' (NICE, 2012). These measures could be seen to develop coping, sense-making and resource building (Nicholson, 1990) in individuals with ASC, and are congruent with intrinsic motivation (Gagne and Deci, 2005), choice and anticipation (Blair, 2000) being associated with transition success. Given the recommendations that services should be user led, it is imperative to seek their views, which have been notably lacking to date.

'Adjustment' in transition is characterised by role changes and behaviour change, requiring practice and solidification (Nicholson, 1990). Work placements have been shown to almost double the chance of successful employment for individuals with ASC, with competitive employment and supported employment rates reported as 84.3% and 82.4% respectively (Ozonoff et al., 2003). This suggests

placements should play a central role in supported transition to work. Service-user perspectives may provide useful information on developing more effective provision.

Employing organisations and supporting agencies also need to consider their role across all stages of transition (Nicholson, 1990), when employing an individual with ASC. For example, Nesbitt (2000) states that organisations are more likely to employ an individual with ASC if they have a greater understanding of the condition, highlighting the need for increased informational support (Sherbourne and Stewart, 1991) in transition 'Preparation' (Nicholson, 1990) for employers.

Supported employment

Individuals with ASC are more likely to be recruited if additional work support is provided by an external agency to aid in the transition (Nesbitt, 2000). Supported employment may relate to the 'Stabilisation' phase of the transition process (Nicholson, 1990). Based on available evidence, NICE (2012) recommends that transition support continues after employment has been obtained. However, few studies consider the longer term outcomes of supported employment (see extended paper, section 4.5.8.) and none consider the experiences of the individuals within this process.

Howlin et al. (2005) conducted an 8 year evaluation of the National Autistic Society's (NAS) supported employment programme which works with employers to support in the recruitment, training and retention of staff with ASC (NAS, 2011). They report approximately 68% of clients had been successfully supported into

employment (Howlin et al., 2005); significantly higher than the 31% ASC employment rate reported (Howlin et al., 2004).

The potential benefits of successful transition to work for individuals, employers and society are clear. Individual experiences and views are noticeably lacking from the existing evidence base on which current service provision is designed and delivered. This not only neglects an important source of valuable information, but also directly contradicts the supposed person-centred principles at the heart of recent legislation (DoH, 2010) and guidance (NICE, 2012).

Aims

This investigation aimed to understand the experience of transition to work from the perspective of a sample of participants with ASC and to identify salient and frequent themes that might aid in the development of more effective transition to work for this population. It is hoped the findings will provide a service user perspective on how transition to work can be effectively supported and made sustainable, whilst minimising distress and maximising self-determination, quality of life, emotional well-being and socio-economic gains.

3.3. Method

Methodology

This study used a qualitative thematic analysis methodology to investigate how participants with ASC experienced their transition to work and the support they received. Thematic analysis allows for the analysis of a large amount of data from multiple participants to be analysed and synthesised into a meaningful account (Boyatzis, 1998). It provides a structured methodology for identifying key themes within a data set and is not constrained by one specific epistemological position (Boyatzis, 1998). Braun and Clarke's (2006) guidelines on thematic analysis were used as they offer an up-to-date description of the method. Beutow's (2010) conceptualisation of thematic analysis as 'saliency analysis' was integrated into this approach, to facilitate the identification of the most salient themes.

An inductive thematic analysis of semantic information from interview transcripts was used in order to develop 'bottom-up' themes (Braun and Clarke, 2006). An advantage of an inductive approach is that it is open to participants' experiences, rather than seeking views on topics informed by the evidence base. This helps to avoid assumptions and biases in the literature being perpetuated (Braun and Clarke, 2006) and limits the influence of the researcher's pre-existing belief; that transition to work benefits individuals with ASC. Although the use of retrospective interviews presents issues relating to the reliability of recall, Blane (1996) suggests events that are particularly salient for an individual are likely to be more easily remembered. (For further details on thematic analysis, see extended paper, section 5.5.).

Epistemology

The investigation was approached from a critical realist epistemological perspective (Robson, 2002). Critical realism holds that knowledge or 'truth' can exist and be shared by a number of individuals, but each individual's experience of truth will be influenced by their own subjective constructions (Robson, 2002). Truths effectively gain weight, or saliency, by accumulating evidence. This study sought to identify common 'truths' in the experiences of 10 participants with ASC who had experienced transitioning to work, by focussing on responses to open interview questions. (For further epistemological considerations, see extended paper, section 5.4.).

Participants[3]

10 adults with ASC who had experienced a transition into work were recruited using an opportunistic and purposive sampling strategy (Robson, 2002). Eight participants were recruited through three separate voluntary sector agencies that specifically support individuals with ASC to find and maintain employment. An advert for participants was placed on the NAS website (appendix 11) and yielded a further participant. The last was referred by an earlier participant. In accordance with qualitative methodology, the aim was to find a small homogenous sample relevant for the study (Lyons and Coyle, 2007). A sample of 10 was considered practical, given the constraints of this study, whilst also being appropriate to capture sufficiently rich and detailed information about participant experiences of transition, rather than risk more superficial analysis often associated with larger sample sizes (Boyatzis, 1998). Table 1. provides an overview of the participant

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[3] Pseudonyms have been assigned to protect participant confidentiality.

descriptive data. (For additional recruitment information, see extended paper, section 5.1.).

Inclusion criteria

18 years old or older

Capacity to provide informed consent

Diagnosis of an ASC (corroborated by supporting agency)

Memory of experiencing a transition

Exclusion criteria

Lack of capacity to consent

Issues of risk identified by the care team, researcher or participant

Interviews

The study used a semi-structured interview schedule (appendix 7). Interviews were audio recorded and conducted in locations that were convenient for the participants, most commonly their home or work place setting. The interviews were transcribed by a paid professional transcription service, bound by a confidentiality agreement (appendix 6). (For further considerations on interview development, see extended paper, section 5.2.).

Table 1. Participant demographic information

Participant pseudonym	Age	Gender	Ethnicity	Estimated age at diagnosis	Employment Status	Approximate hours worked a week	Remuneration	Benefits
Donald	49	Male	White British	46	Unemployed	0	-	Yes
Brian	32	Male	White British	30	Employed	30	Paid / voluntary split	Yes
Samson	26	Male	White British	19	Employed	16	Voluntary	Yes
David	21	Male	White British	5	Unemployed	0	-	Yes
Elliott	30	Male	White British	27	Employed	Up to 50	Paid	No
Andrew	27	Male	White British	26	Unemployed	0	-	Yes
Frank	21	Male	White British	20	Employed	6	Paid / voluntary split	Yes
Jane	20	Female	White British	17	Employed	7	Paid	Yes
Jade	24	Female	White British	21	Employed	8	Paid	Yes
Bruce	23	Male	White British	5	Employed	16	Paid	No

Table 1.

Analysis

Braun and Clarke's (2006) phases of thematic analysis were followed. Firstly, interview transcripts were read and ideas were noted down in a process of familiarisation. Secondly, line by line coding was conducted to generate the initial codes (appendix 8). The whole data set was grouped together under similar codes and then sorted into initial themes (appendix 9). Saliency analysis (Buetow, 2010) of themes involved consideration of the frequency of data within the theme and the perceived importance of that theme. Themes were identified as salient if supported by participant statements such as "the most important thing is...", and frequent if a high number of participants raised the same theme, not on the basis of frequency of comments. Themes were discarded if found to be neither salient nor frequent (Buetow, 2010). (For further details on analysis, see extended paper, section 5.7.).

Themes were then reviewed, refined, defined and considered in relationship to each other in a 'theme map' (see Fig 1. and extended paper, section 6.4.). The analysis appeared to reach thematic saturation, indicating an appropriate sample size (Lyons and Coyle, 2007). All stages of the analysis were peer reviewed by the second author and quotations used to represent themes were subject to 'member checking' with the relevant participant, as suggested by Robson (2002). This was done via email or phone, according to the preference of the participant. The original interview transcripts were then re-read to ensure the final themes were supported by the original data. (For further details on analysis, see extended paper, section 5.7.).

3.4. Results

Three main themes relating to transition to work were identified from the data: 'Diagnosis', 'Barriers to transition' and 'Transition support'. These were all considered to be frequent themes within the dataset and highly salient for the majority of the participants. Although a central theme was not found in this sample, we suggest the three main themes can be synthesised in the tentative statement of "Transition to work can be facilitated by early diagnosis, providing access to appropriate services that offer well planned sustainable support throughout transition, appropriate to the needs and skills of the individual". It is beyond the remit of this paper to address all of the three main themes in sufficient detail (see extended paper, section 6.). 'Transition support' has been focussed on, as this is most relevant to the current context of ASC strategy in the UK, as set out by the DoH (2010) and NICE (2012). Figure 1. shows all identified sub-themes.

Figure 1. Transition support theme map
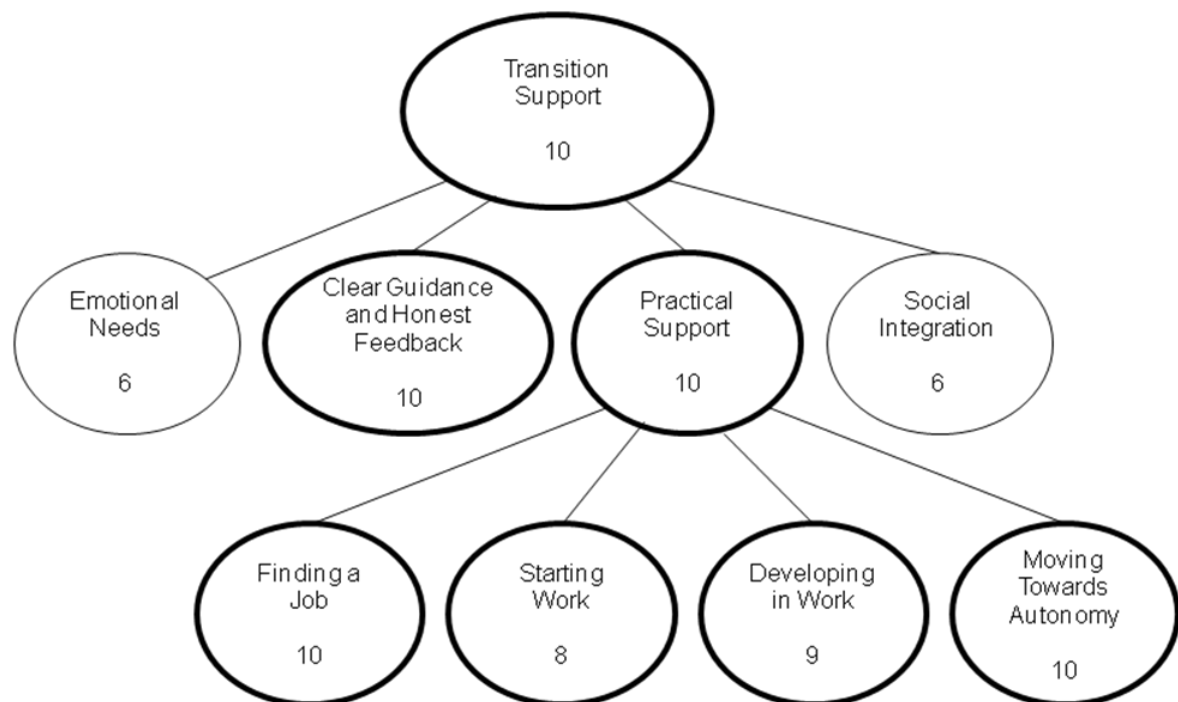
Bold circles: salient themes
Numbers: frequency

Fig 1.

Transition support

All ten participants cited that transition support was fundamental to their transition into employment and in overcoming barriers. Sub-themes of 'Emotional needs', 'Clear guidance and honest feedback', 'Practical support' and 'Social integration' were identified as key factors influencing transition.

Emotional needs in transition were identified by six participants. Anxiety around starting work, disrupting routines and the impact of this on work practices was highlighted:

> About two days before I do anything new, I get really nervous. Just in general days of your life, I am just thinking about it all the time… Like can't do any work or anything. (Frank)

In contrast, confidence was seen as a benefit:

> If you're more confident and better able socially with friends, presumably you'd be better able in work scenarios and interviews and things. (Elliott)

Emotional issues reported related to transition, work and personal factors:

> I weren't firing on all cylinders for a while and I think I am getting back to it now. So it is still the issues of possible depression that comes up... *[sighs]* Erm… The frustrations I have is again accessing training, but there's also trying to be efficient. Trying to get things out as quick as possible, and of course if there's delays, and delays, and delays er… it can be frustrating... There's also a couple of personal issues that I had at the time and I don't know if that's related to why I had a relapse into depression. I am not sure about that, but it is a theory I have. (Brian)

Despite the emotional needs highlighted, only two participants reported that they received specific emotional management training or therapy:

And it were almost like more of a therapy session, it weren't just about job search, because they acknowledged that, no, we didn't need that...I got the support, you know, there were all things about confidentiality, we had a secure room and the women who worked there couldn't just walk in and out, so we were all done properly and professionally. And I felt that I wasn't alone, because at the time I felt I were the only forty-five year old bloke in [place A] who'd never had a job. (Donald)

 [The support] suggested erm… to… if the situation resulted in anger, walk away from the situation. Or if the situation resulted in… much anxiety, to try and… to try and take deep breaths, or something. And erm… and er… it was like to get advice, to get the right advice up on… on anxiety, and try to overcome it in the right way possible. (Samson)

Clear guidance and honest feedback was identified by all participants as critical in transition, to support their control and commitment (Ronka et al., 2003). Advice and clear information about options was desired by most:

[Support] just needs to be a little bit clearer, and er… in what's the right thing and what's the wrong thing [for me] to do, you know…. The thing I would mention [that's needed] is clearer advice and rules and regulations. (Samson)

I was there for about a few months but I didn't know what I wanted to do with my life. I had a ton of skills but I didn't know which direction to take. (Brian)

Interviewer: How do you think [the support agency] could be more helpful?
Like give you more like advice and stuff or ask us if we need help or anything.

Interviewer:	And if they were able to do that, what areas would you want advice on, or do you want help with?

I would say like… a better chance like… how to do like your CV and get a job like… where you are going wrong and everything. (Jane)

Participants received guidance and feedback from families and support agencies, particularly valuing this when it identified their strengths and weaknesses in relation to transition to work, as recommended by NICE (2012), and considering individual variation in skills and impairments:

My mum felt [the job] might be too difficult, because then I weren't… like hadn't much confidence or anything. (Jane)

I think the absolute first thing [the ASC support agency's] got to do… you've got to say it's not everyone with Asperger's is the same in terms of what they are good at and aren't good at, and what they find easy to deal with and what they don't. Yeah, and [ASC support agency] were sort of, sort of profiling I suppose on what I was good at and what I was like. (Elliott)

In line with NICE (2012) recommendations, some participants highlighted the utility of have a caseworker assigned to them; to support in developing work interests and identifying strengths:

That was good, [ASC support agency] had a caseworker assigned to me who did lots of work around what I was good at and what I thought I was looking for. (Eliiott)

Participants stated a strong preference for honest communication, in order that they might best understand their situation and development needs:

I suppose before I had a number of jobs, applying for them and then not getting a response. If they're not going to give you a job, it's better to at least know that you're not going to get a job, 'cos otherwise you've got like a false sense of hope. I mean if you're not going to get a job, fair enough, they should at least tell you. (Andrew)

To be honest I respect someone to be more honest with me rather than sort of hurt my feelings. Because it has got to be said to me oh that is not good enough, and that's what I need to take on board, that's what I need to understand. I much prefer and I respect honesty. (David)

Practical support was identified by all ten participants as another highly salient factor influencing their transition experiences. More so than other subthemes, practical support varied in relation to different transition stages, identified by four further subthemes; 'Finding a job', 'Starting work', 'Developing in work' and 'Moving towards autonomy'.

Finding a job. All participants felt support was necessary at this stage. Participants reported support agency links and communication influenced their ability to access appropriate support finding jobs, as highlighted by Schall and McDonough (2010). Some also identified the involvement of education services, as recommended by Hendricks and Wehman (2009):

Interviewer: So what did [the support agency] do wrong, other than not find you the work placement?

Well, I was supposed to have gone in to do job searches, and they didn't get in touch.

Interviewer: What should they have done differently?

Well communicate… and help me with my job search to look for a job. (Jade)

It was school that took me to the [ASC support] agency, 'cos the school and the agency were connected somehow…. They're the same [support] agency that found me the supermarket [job].

Interviewer: And now you're working for [the ASC support agency] directly?

Yeah. Fully. (Bruce)

Participants reported both positive and negative experiences of services helping them prepare for work, with a clear tendency for ASC specific services to be viewed positively, and generic services negatively. Most felt they benefitted from support in developing their CV and applying for jobs, but some highlighted frustration with communication and inappropriate support:

Well the [ASC support agency] like they help you to do your CVs and that, which is good. (Jane)

[The Job Centre] make you do a CV and then they make you read a newspaper five days a week looking for a job. But they make you read the same newspaper every day with the exact same jobs that were in yesterday. (Andrew)

Job interviews, the associated social difficulties and support received were frequently highlighted:

In the interview there is a problem, because I don't speak clearly in interviews. I realised I mumbled. (Frank) (see critical reflection, extended paper, section 8.2.)

Like your interview and that. They [ASC support agency] do like a role play like to get you like so you know what to do. (Jane)

Starting work. Eight participants felt support starting work was essential. Having access to an advocate working into employing organisations was valued, as recommended by NICE (2012):

> Have a person go there and act as an advocate paving the way for me. So, yeah, it would be a two-way thing and probably I would be expecting more from them, than they could expect from me. Because that's as it is, I haven't got the resources financially or personally within in me. (Donald)

Participants attended training courses, of variable benefit, in support of them starting work:

> For while I was doing the courses and that… It was for erm… it was for the specific courses I was doing, and the specific work. [ASC support agency] did provide a support… support for… into the world of work. (Samson)

> I did all training courses in between [at The Job Centre]... Well they say training, allegedly training courses, not very interesting training courses. Well, apart from one... (Andrew)

Developing in work. Nine participants felt support to develop them in work was necessary. The majority of participants who had successfully transitioned into sustained employment reported a supported gradual increase in hours, towards full time work:

> When I first come to [the ASC support agency]… they found me the work placement, and I worked… [I] started off working three hours, then it were built up to a full day, which were eight hours, eight and a half hours. (Jade)

Supported work placements, as recommended by NICE (2012), were regarded as helping to increase confidence, work practices and enjoyment:

> The most useful part was the work placement bit, which allowed me to be… get a bit more confidence in it, and er… and to… and the trying… to try and do the appropriate actions that an employee would do. (Samson)

> [The placement] really did give me that massive boost in confidence, encouragement to find some more work that I were enjoying, and to do that I thought was quite good. To have the work experience doing something like that is something pretty cool. (David)

Moving towards autonomy. Autonomy in work was desired by all participants. Continued but reducing support, as suggested by NICE (2012), was seen as a key factor in sustaining transition and decreasing reliance:

> I do get support probably about six to… maybe coming up to [once every] two months, at least, but I do get it now and again, and not a right lot as I used to have.

> Interviewer: Okay. Is that something that you see as a good thing?

> Yeah. Because the [support] agency says to me if I need any help, that if there's anything that I'm struggling with, or I'm not sure, to go to the agency as well as going to the company. (Bruce)

Employment was reported to lead to personal gains, benefitting work and wider social roles:

> When I have been at [employer] it has really gathered all my confidence up as well. By being with people. It was like before I weren't good like talking to people, now I am fine with that. (Jane)

Since [working]... I feel like I've improved, become more social, like… and everything like that, because I've been mostly quiet through my entire life. (Bruce)

Social integration was cited by six as influencing their transition. Some described mutually beneficial relationships with their colleagues, characterised by trust and acceptance:

My colleagues helped me, support me, did everything they can to help me get those targets and objectives done. And they helped take the pressure off of me, and I helped take the pressure off of them as well at the same time. Because they knew that I could get the job done, and they would help me get the job done as [well as] I possibly can. (Bruce)

Participants reported a sense of belonging and community, developed through social contact with others with ASC:

And I felt that I wasn't alone, because at the time I felt I were the only forty-five year old bloke in [place A] who'd never had a job, which might well be the case. But at least now I'm not the only person who has got Asperger's who has never had a job. So there's a community. (Donald)

3.5. Discussion

This study aimed to investigate and understand the experiences of individuals with ASC as they transition into employment settings in the UK. Thematic analysis of interview transcripts identified frequent and salient themes in the data relating to 'Diagnosis', 'Barriers to transition' and 'Transition support'.

The views participants expressed in this study are largely congruent with the suggested guidelines for adults with ASC (NICE, 2012) and government strategy for ASC services (DoH, 2010). However, this study also provides a valuable insight into service user transition experiences, which is largely neglected by these documents. In order to further consider the implications of this study, improve clarity and facilitate discussion, the experiences of transition support received by this sample will be considered in relation to the four functions of support (Sherbourne and Stewart, 1991) and four stages of the transition cycle (Nicholson, 1990). Clear overlap with these models is evident, as well as differences. They provide a useful framework, despite inflexibility and over-simplification, implicit in categorical models. All four types of social support (Sherbourne and Stewart, 1991) were identified as necessary across all transition stages (Nicholson, 1990).

Themes identified as highly salient relate to practical; tangible and informational support, perhaps due to impaired social and emotional understanding in ASC (Downs and Smith, 2004) drawing focus away from emotional and relational supports. Therefore, whilst this reflects participant perspectives in this study, it does not necessarily lessen the importance of these supports during transition.

The need for emotional support (Sherbourne and Stewart, 1991) was evident throughout the transition cycle (Nicholson, 1990). It is notable that the subtheme was identified as 'Emotional needs' rather than 'Emotional support'. Despite predictable emotional distress as a result of any change process (Berney, 2004), this is one of the more neglected aspects of transition research relating to ASC. Only two participants received any emotional support, highlighting that support agencies must ensure emotional, as well as practical, needs of service users are attended to during transition. Agencies must remain mindful that individuals with ASC might not draw attention to their emotional needs and be proactive in assessing these and offering support so as to benefit service users and minimise distress (Sherbourne and Stewart, 1991). Clavenna-Deane (2011) reports on a Cognitive Behavioural Therapy programme which demonstrated improved employment experiences for adults with ASC, which may be useful in this context.

'Clear guidance and honest feedback' relates to 'information and appraisal support' (Sherbourne and Stewart, 1991) and applies across all stages of the transition cycle, from advice in 'Preparation' to employer feedback in 'Adjustment' and 'Stabilisation' (Nicholson, 1990). A key message is that individual strengths need to be assessed, as recommended by NICE (2012), facilitating development of realistic expectations, targeted career planning and appropriate job matching. The desire for continued information and appraisal support (Sherbourne and Stewart, 1991) throughout transition was a highly salient issue for participants. It is understandable, due to impaired social understanding in ASC (APA, 2010), individuals would want feedback on their attributes and skills in occupational situations. This promotes self-determinism (Gagne and Deci, 2005) and develops

self-efficacy, self-esteem and emotional well-being (Bandura, 1997), increasing the likelihood of transition success and sustained employment (Ronka et al., 2003). The individual impact of failed transition was not pertinent, as most (eight) participants were reflecting on experiences culminating in employment.

Transition planning and goal setting (Hendricks and Wehman, 2009) was not explicitly reported, but occurred to some extent through skills, needs or job matching assessments. Actively involving individuals in setting explicit targets and transition goals might further reduce distress in transition, through increasing self-determinism (Gagne and Deci, 2005).

For participants, having a 'case-worker', 'advocate', or 'job coach' provides opportunity for both information and appraisal, as well as tangible support (Sherbourne and Stewart, 1991), mainly in the earlier stages of transition (Nicholson, 1990). If one professional was able to fulfil all of these roles (NICE, 2012), individuals with ASC would only have to navigate one relationship. Development of such a relationship may also create opportunities for 'emotional' and 'positive social interaction support' (Sherbourne and Stewart, 1991), helping further minimise distress (Cohen and Hoberman, 1983). Advocacy to employers increases the chance of employment (Nesbitt, 2000) and may help to reduce potential for 'out-group' prejudice (Tajfel and Turner, 1986) and victimisation, resulting from increased understanding. This supports NICE (2012) recommendations that potential employers need to be fully educated about ASC.

Within 'Practical support', different stages of transition were reported to require different support mechanisms, far more so than for other support types. These were identified by different subthemes, sharing commonalities with stages of the transition cycle (Nicholson, 1990), as illustrated below.

'Finding a job' largely relates to transition 'Preparation' in which individuals develop expectations, motives and feelings related to transition (Nicolson, 1990). It is paramount that services, including education, link and share information from early in the transition process (Hendricks and Wehman, 2009). However, poor communication in support is prevalent in many areas of health and social care in the UK, as highlighted by a number of public inquiries (e.g. Laming, 2003). Improving communication within and between services is essential to facilitating transition and minimising distress for individuals with ASC, as poor communication leads to impaired self-determinism and feelings of powerlessness (Gagne and Deci, 2005).

The social nature of job interviews does not correspond well with the characteristics of ASC (Berney, 2004) and no evidence suggests strategies to support in this. This study highlights how simple supports could improve individual experiences of interviews. Support services and job coaches could offer role plays, support in interviews, arrange work trials, match jobs to skills and act as a source of information and communication link between all stakeholders, as recommended by NICE (2012).

Advocates, or job coaches, also provide beneficial support when 'Starting work', related to transition 'Encounter' (Nicolson, 1990), involving confidence building, coping and sense-making. This highlights the utility of having access to the support of key individuals throughout transition.

Training courses supporting individuals with ASC starting work are often poorly received. This may be due to inappropriate skills or needs appraisal, or trying to provide group training to a population with diverse needs, resulting in inappropriate content. There was a noticeable difference between the perception of support received from ASC specific services and statutory generic services, with the former being reported more favourably in this study. This was also noticeable in 'Finding a job', reaffirming the importance of support agencies having appropriate knowledge, information and skills when working with ASC (DoH, 2010). This variation may be due to differences in specialist knowledge, or increased likelihood of groups containing similar individuals, supporting the development of a common social identity, in-group cohesion (Tajfel and Turner, 1986) and opportunity for 'positive social interaction support' (Sherbourne and Stewart, 1991).

Practical support in 'Developing in work' mostly relates to transition 'Adjustment', characterised by personal change, role development and relationship building (Nicolson, 1990); in direct conflict with social difficulties and rigid behaviour implicit in ASC (APA, 2010). The gradual increase in work hours desired by participants would gradually expose individuals to changes in routine and behaviour, limiting anxiety and distress. Providing individuals with choice around increasing hours will

again promote self-determinism (Gagne and Deci, 2005) and associated benefits. Work placements provide an opportunity for this, for practising work behaviours and developing in role (NICE, 2012).

'Moving towards autonomy' relates to transition 'Stabilisation', involving increased commitment and effectiveness (Nicolson, 1990). Within this sub-theme, the real benefits of supported transition are evident. Participants reported significant behavioural change, characterised by increased self-efficacy, emotional well-being and work performance (Bandura, 1997). Within this context, it is possible to envisage the speculative individual and socio-economic benefits suggested (NICE, 2012) might be realised. Continued support in employment (NICE, 2012), with gradual movement towards autonomy, is essential to maximise these gains and ensure sustained employment.

'Social integration' relates to 'positive social interaction support' (Sherbourne and Stewart, 1991) within support groups and work environments, throughout the transition cycle (Nicholson, 1990). Despite social and communication difficulties implicit in ASC (APA, 2010), a desire and capacity to experience companionship in occupational contexts exists. Positive social interaction reduces the likelihood of receiving 'out-group' prejudice (Tajfel and Turner, 1986) and benefits social identity (Holland et al., 1998), self-esteem, self-efficacy and emotional well-being (Bandura, 1997). Peer support groups provide this support function well (Weidle et al., 2006), but were accessed by a minority of participants, highlighting how easily emotional and relational needs of individuals with ASC can be overlooked.

The recruitment strategy for this study is a potential limitation. All participants, except one, were recruited through connections to specialist ASC employment agencies and seven out of the 10 were currently employed in some capacity. All of the individuals interviewed believed that appropriate employment support was essential to their transition success. Although this sample provided an enlightening insight into their experiences of transition to work, these may not transfer very well to the ASC population as a whole. This sample provides an informative account of the experiences of individuals receiving support for transition to work and their views on the strengths and weaknesses of service provision.

Summary

Ten UK participants that had experienced transition to work highlighted how a wide range of support was beneficial to their transition experiences. Support functioned to meet emotional, tangible, informational or social needs (Sherbourne and Stewart, 1991) in preparing, encountering, adjusting and stabilising the transition (Nicholson, 1990). This adds a valuable service user perspective in support of the NICE (2012) guidelines. The application of psychological models of support and transition serve as useful frameworks for developing comprehensive support packages that best meet individual needs, promote self-determinism (Gagne and Deci, 2005) and increase the likelihood of obtaining and sustaining employment.

Understanding transition will best enable services to alleviate service user distress through support (Cohen and Hoberman, 1983), offer truly person-centred care

supporting individuals to pursue their choice for work, leading to individual benefits in self-efficacy, emotional well-being (Bandura, 1997) and quality of life (NICE, 2). Suggested secondary benefits of supported employment, including reduced costs associated with supported living and accessing mental health services (NICE, 2012) may also be realised.

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Part II. Extended Paper

Autism and Transition to Work: A Thematic Analysis of Service User Experiences

4. Extended background

This section provides an overview of literature relevant to autism and transition to work.

4.1. Autism

For the purposes of this thesis, it is important to consider the historical development of the concept of 'Autism', how it is currently understood and how it is perceived by those diagnosed with the condition.

4.1.1. Terminology

The term 'autism spectrum condition' (ASC) will be used throughout this paper to inclusively refer to all descriptive titles of pervasive developmental disorders that impact upon social communication ability and rigid and repetitive behaviour. The justification for this can be found below under 'Autism and labelling' (extended paper, section 4.2.2.) and 'Diagnostic considerations' (extended paper, section 4.1.3.). On occasion, the term 'autism' will be used as a short hand version of this, in order to improve the readability of the paper, but this is intended to imply the same concept. Asperger's syndrome is referred to at times, mainly when reporting other people's studies or providing quotes and is often shortened to 'Asperger's'. This is considered to apply to individuals with ASC who do not have an associated learning disability, which is conceptualised as an IQ below 70 (American Psychiatric Association [APA], 2000). Individuals above the learning disability cut-off are often referred to as 'higher functioning'. 'Neuro-typical' refers to people without a diagnosable neurological disorder, such as autism.

4.1.2. History of autism

Wing and Potter (2002) provide a detailed account of the historical development of autism, which is summarised below. They comment on how numerous accounts of 'odd behaviour' in history suggest that autism has existed long before being named and defined. 'Early infantile autism' was introduced by Leo Kanner in 1943 and characterised by severe impairments in social interaction, communication and resistance to change. Slightly after Kanner published his paper, in 1944, Hans Asperger published a study on 'autistic psychopathy', which later became known as Asperger's syndrome. Asperger (1944) described similar behaviour patterns to Kanner (1943), but in a more able population. However, Asperger's paper was written in German and not well known in English speaking countries until Wing (1981) published a detailed account of his work and a full translation was then published in 1991 (Frith, 1991). Around this time, the notion that autism was a rare condition began to be challenged and studies on prevalence suggested that rates of autism might be increasing (Wing & Potter, 2002). Wing and Gould (1979) identified a 'triad of impairments' within autism, relating to social interaction, communication and flexibility of thought and imagination. They suggested that each of these can impact individuals to differing degrees, informing the conceptualisation of autism as a spectrum disorder (Wing, 1997). This, along with the other research mentioned above, informed much of the current understanding of autism and diagnostic systems used to identify it.

4.1.3. Diagnostic considerations

Barnard, Harvey, Potter and Prior (2001) found that early diagnosis of autism related to satisfaction with education provision, but there was a significant pattern of late diagnosis across all individuals they surveyed. 57% of lower functioning adults on the ASC spectrum were not diagnosed until at least five years of age and 18% were still not diagnosed until after the age of 16. For people with Asperger's syndrome diagnoses, representing the 'higher' end of the ASC spectrum, 46% were not diagnosed until after the age of 16 (Barnard et al., 2001). More recent studies (e.g. Brugha et al., 2011) highlight under-diagnosis remains a problem but do not offer figures on how increased awareness and service provision may have impacted on this over the past decade.

Autistic disorder

Autistic disorder is a developmental disorder, under the diagnostic umbrella of Pervasive Developmental Disorders in the International Classification of Diseases, 10th Revision (ICD-10) (World Health Organisation [WHO], 1992) and Diagnostic and Statistical Manual of Mental Disorders, 4th edition, text revision (DSM-IV-TR) (APA, 2000). According to the DSM-IV-TR, it is characterised by qualitative impairments in three domains of social interaction, communication and restricted, repetitive and stereotyped behaviour, interests and activities (APA, 2000). These three domains are frequently referred to in the literature as 'the triad of impairments' and described as deficits in social interaction, communication and imagination (Wing, 1997). The two diagnostic manuals qualify autistic disorders in very similar ways, although subtle differences do exist between the two, mainly in terms of the terminology used. For simplicity, only the DSM-IV-TR (APA, 2000) diagnostic criteria are discussed here.

Impairments in social interaction may be recognisable by impaired use of multiple non-verbal behaviours such as eye gaze, facial expression and body posture (APA, 2000). Individuals with Autistic disorder often fail to develop peer relationships appropriate to their level of development and present with reduced spontaneous sharing of enjoyment, interests and activities with others. They often show a lack social or emotional reciprocity (APA, 2000).

Impairments in communication manifest as a delay or lack of spoken language development (APA, 2000). In individuals with adequate speech, they often struggle to initiate or sustain conversations, use stereotyped, repetitive or idiosyncratic language and lack imaginative or imitative skills (APA, 2000).

Restricted, repetitive and stereotyped behaviour is often characterised by abnormally intense or focussed preoccupations with one or more stereotyped and restricted pattern of interest (APA, 2000). Individuals often appear inflexible and adhered to non-functional routines or rituals and may present with stereotyped and repetitive motor mannerisms, such as hand-flapping. They may also show persistent preoccupation with parts of objects (APA, 2000).

It is a categorical requirement for diagnosis that abnormal functioning in either social interaction, language used in social communication and symbolic or imaginative play is considered to have manifested prior to the age of three (APA, 2000).

Asperger's disorder

The diagnostic category of Asperger's disorder also comes under the umbrella of Pervasive Developmental Disorders (APA, 2000) and is referred to as Asperger's syndrome in the ICD-10 (WHO, 1992). Asperger's disorder is characterised by the same impairments in social interaction and repetitive, stereotyped behaviour as Autistic Disorder but, for diagnostic purposes, individuals must also present with clinically significant impairment in social or occupational functioning. Individuals must also be considered to not be significantly delayed in their cognitive development, self-help skills, or adaptive behaviour (APA, 2000). Wing (1997) proposed that ASC is best conceptualised as a spectrum, with varying severity of impairments affecting individuals to varying extents. Asperger's disorder has traditionally been viewed at the milder end this spectrum (Wing, 1997).

The future of diagnosis and the DSM-V

The fifth edition of the DSM is due to be published in 2013 (APA, 2010) and is likely to include some revisions to the diagnostic categories for pervasive developmental disorders, based on and incorporating up to date research and expert opinion from the 12 years of research since the DSM-IV-TR (APA, 2000) was published. Most notably, Autistic disorder and Asperger's disorder will be subsumed under the diagnostic category of Autism spectrum disorder (ASD), along with childhood disintegrative disorder and pervasive developmental disorder not-otherwise specified (APA, 2010). The three domains of impairment will become two, as impaired social interaction is clearly and inextricably linked to impaired social communication. Therefore, ASD will be defined by 'social and communication deficits' and 'fixated interests and repetitive behaviours' (APA, 2010). Sensory processing differences will be considered within the latter and defined as "Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment" (APA, 2010). These sensory abnormalities may

present as indifference to pain, heat or cold, adverse responses to specific sounds or textures or excessive smelling or touching of objects and fascination with lights or spinning objects (APA, 2010). The DSM-V (APA, 2010) is also likely to state that symptoms may not fully manifest until social demands exceed the limited capacities of individuals with ASD, thus highlighting that, although ASD is a lifelong disability, it may not be noticeable until later in life. In the context of transition to work, the social demands of finding and maintaining work may be the first instance of exceeding an individual's 'limited capacity'.

4.1.4. Epidemiology of autism

There has been a great deal of debate and dispute around autism prevalence rates. An Office of National Statistics survey of children and young people in Britain reported a prevalence rate of 0.9% for ASC (Green, McGinnity, Meltzer, Ford & Goodman, 2005). Baird et al. (2006) reported a similar overall prevalence of 1.16% for ASC in children in a UK sample, but noted that few individuals with Asperger's syndrome were identified, suggesting that a limitation of the study was that children would not have been recruited if they were in a mainstream school and did not have a statement of special educational needs. They therefore suggested that this prevalence rate should be considered a minimum estimate (Baird et al. 2006). A meta-analysis of the extant literature by Newschaffer et al. (2007) reported the prevalence of ASC to be nearly 6 per 1000 in children; less than a third of these related to 'autism', with the majority representing the 'higher-functioning' end of the spectrum (for consideration of this terminology see extended paper, section 4.2.2.).

Prevalence rates for ASC are higher for males than for females in both adult (Brugha et al., 2011) and child (Yeargin-Allsopp et al., 2003) populations, at a ratio of up to about four to one, but this ratio was reported to be decreased in lower functioning samples (Yeargin-Allsopp et al., 2003). A National Autistic Society (2008) survey of adults in the UK reported a 2:1 male to female ratio. Prevalence rates are higher for those with no educational qualifications those in government financed accommodation and those living in 'more deprived wards', highlighting

how individuals with ASC are at increased risk of social disadvantage (Brugha et al., 2011).

Schall and McDonough (2010) suggest that this level of prevalence represents an increase from previous levels, highlighting that the reported prevalence in 1990 was estimated at 4 to 5 per 10,000. Fombonne (2005) reports that the median prevalence rate in 16 surveys published between 1992 and 2001 was 12.7 per 10,000 compared to 4.4 per 10,000 from 16 studies between 1966 and 1991. Wing (1996) suggests that most of the variation in prevalence rates could result from differences in definitions of ASCs and in defining subgroups within the spectrum. It is also likely that ASC is being diagnosed more frequently, despite the prevalence remaining unchanged in real terms, as a result of diagnostic criteria changing, increased awareness of ASC amongst society, parents and professionals and the development of more specialist services (Wing & Potter, 2002). Brugha et al. (2011) state it is likely that over 50% of individuals with an ASC have average, or above average intelligence and some of these will be very able intellectually. Many of these individuals are unlikely to come to the attention of services as they have learned to cope with communication and social interaction difficulties. Many may have found employment well suited to their particular talents. However, the possibility that ASC prevalence is indeed increasing cannot yet be ruled out (Wing & Potter, 2002).

In a recent study, Brugha et al. (2011) surveyed 7461 randomly selected adult participants and identified 9.8 individuals with an ASC per 1000 through a screening process followed by diagnostic interviewing. This was the first study of ASC prevalence rates for an adult UK sample. Prevalence was found not to be related to age in this sample and reported at a similar rate to studies of child populations; prevalence would be expected to be higher in child samples if ASC was becoming more common (Brugha et al., 2011). Whether the increase in prevalence of ASC is real, or perceived, as a result of diagnostic variations and trends, is to some extent less relevant than the question of how to meet the social and economic needs of this group (see extended paper, sections 4.1.7. and 4.3.). Gerhardt and Lainer (2010) state that 70% of ASC diagnoses relate to people under the age of 18. They suggest that a surge of children with ASC are about to

leave school and enter adulthood, which Wazana, Bresnahan and Kline (2007) refer to, rather derogatorily, as 'the autism epidemic'. Gerhardt and Lainer (2010) highlight that adult services are already stretched and unlikely to obtain extra funding to manage the increased need, given the current poor economic situation in the UK, emphasising the necessity to reduce the economic pressures of ASC. Supporting individuals to obtain and maintain employment may be an effective strategy, as well providing individuals with an opportunity to thrive and achieve to their full potential (see extended paper, section 4.5.)

4.1.5. Aetiology of autism

Huge amounts of research has been conducted into the potential causes of autism and this has usually been centred on the aim of finding a cure. This has led to much controversy within the autistic community, as many individuals feel that autism is a neurological difference, rather than a 'disease' which needs curing. Controversy has also permeated the scientific community around issues such as whether the combined measles, mumps and rubella vaccine can cause autism. Wing and Potter (2002) state explicitly that no environmental factor has sufficient evidence to support that it causes autism and that genetic factors are universally accepted as the most significant aetiological component.

Happé and Ronald (2008) have suggested a 'fractional' model of the triad of impairments and autism, based on aetiological research. They found that specific identified 'causes' related meaningfully to one element of the triad of impairments, but not others. For example, one aetiological factor may have a strong association with social deficits in autism, but not with the repetitive component of the disorder. This suggests that autism may be an 'umbrella' term for a number of distinctive, yet frequently associated, symptoms of potentially different disorders. However, where one draws the line between what is considered a symptom and which cluster of symptoms constitutes a disorder, remains somewhat of an arbitrary process.

4.1.6. Models of autism

Baron-Cohen, Leslie and Frith (1985) found that autistic children are less able than neuro-typical children and those with Down's syndrome to consider that others may hold different desires and beliefs to their own. This ability is often referred to as 'Theory of Mind' and represents one of the first attempts to develop a cognitive model of ASC. More recently, this has also been referred to as 'Mind-blindness' (Baron-Cohen, 1995) and perhaps can be more simply conceptualised as the ability to perspective-take. Children with ASC were found to be consistently more impaired in perspective-taking ability, even after mental retardation was controlled for (Baron-Cohen, Leslie & Frith. 1985). Even high functioning individuals with ASC have been shown to present with subtle impairments in 'mind-reading' ability (Baron-Cohen, 2000). Wellman, Cross and Watson (2001) conducted a meta-analysis of 'Theory of Mind' evidence and support the validity of this concept on the basis of their findings.

Theory of mind ability can be broken down into five increasingly sophisticated levels of learning comprising of; understanding how other people see things; how other people can see things differently, how seeing things leads to knowing, how actions are based on true beliefs and finally, how actions can be based on false beliefs (Barnes-Holmes, Barnes-Holmes, Stewart & Boles, 2004). This staged model may account for the spectral variation of symptoms experienced by individuals with ASC. Barnes-Holmes et al. (2004) suggest that deficits in perspective-taking can be accounted for by considering a Relational Frame Theory (Hayes, Barnes-Holmes & Roche, 2001) explanation. Increasing difficulties in forming derived stimuli relations within relational frames comprised of, for example, 'I – YOU', 'HERE – THERE' and 'NOW – THEN' relations (words in bold constitute stimuli) would account for varying perspective-taking ability and correspond to varying performance on the five levels described (Barnes-Holmes et al., 2004). Murphy, Barnes-Holmes and Barnes-Holmes (2005) suggest that deficits in perspective-taking ability in children with ASC can be alleviated through specific training in deriving relationships between stimuli in relevant relational frames. This application of Relational Frame Theory (Hayes, Barnes-Holmes & Roche, 2001) to ASC is promising, but further research is required.

More recently, Qian and Lipkin (2011) suggest a theory based on learning styles to account for cognitive and behavioural differences in ASC. They suggest that individuals with ASC have a bias towards a 'look up table' (LUT) style of learning which stores experiential information very precisely. This is in contrast to neuro-typical individuals who tend towards 'interpolation' (INT) which is concerned with extracting regularities from experiential information and generalising. It is suggested that LUT learning is inefficient and a dependence on this accounts for difficulties generalising learning in ASC, resulting in poor social skills, communication, rigidity and the pre-disposition for an individual to experience over-load (Qian & Lipkin, 2011). The authors suggest training INT learning strategies to individuals with ASC to help remediate social, communication and rigidity difficulties. This theory perhaps compliments the Relational Frame Theory (Hayes, Barnes-Holmes & Roche, 2001) account of ASC, in that impaired ability to derive relationships between stimuli (including verbal representations of stimuli) makes it difficult to extract regularities and generalise, leading to a more LUT learning strategy and the associated difficulties (Qian & Lipkin, 2011).

4.1.7. Functional differences in autism

As discussed above, the functional impairments in ASC most likely weigh on two factors. One is characterised by social communication deficits and the other by rigid and repetitive behaviours (APA, 2010) and the way in which individuals present is often a complex blend of the two. Individuals with ASC may lack awareness that others are capable of thinking and feeling and their ability to organise, plan and predict outcomes in social settings can be severely limited (Wing, 1997). They often present as egocentric and lacking in empathy, the ability to generalise and only being able to learn social rules by rote (Wing, 1997). Some individuals with ASC have expressed anger that people with autism are often viewed not to have empathy and have suggested that 'neuro-typicals' may be the ones lacking empathy in reporting this (Hurlbutt & Chalmers, 2002; National Institute for Health and Clinical Excellence [NICE], 2012). Individuals are often very sensitive to their difficulties in social settings and experience worries about what others might think of them (Hurlbutt & Chalmers, 2002), which could be argued to demonstrate the ability to perspective take. However, perspective-taking is a

complex skill with various levels of sophistication (for further detail, see extended paper, section 4.1.6.).

Many individuals with ASC also have difficulty expressing their own emotions (Winter-Messiers et al., 2007). Misinterpreted and misunderstood emotions can result in "emotional confusion" and lead to anxiety, low self-esteem, depression and frustration (Winter-Messiers et al., 2007) as well as difficulties with socialisation and communication. Their need for routine, sameness, and predictability often means that they are resistant to change (Meyer, 2001). In addition, people with ASC often process sensory information differently to the general population and may therefore commonly experience either hypo- or hyper-arousal in response to various stimuli (Rogers & Ozonoff, 2005). These may prove complicating factors when considering an individual's transition to the work place.

Special interests areas are a dominant feature of higher functioning individuals with AS (Winter-Messiers et al., 2007) and form part of the restricted, repetitive interests and limited social repertoire common in ASC. Winter-Messiers et al. (2007) suggest a strength based model of ASC, utilising special interests through therapeutic work to help address deficits in social and communicative abilities by engaging the individual in social processes and learning exercises. This may be a useful approach when considering employment opportunities and transition to work for individuals with ASC.

Individuals with ASC tend to demonstrate a bias to local, detail-focussed cognitive processing, rather than a more generalising, global style and this has been termed as 'weak central coherence' (Happé, 1996). Happé and Frith (2006) have been keen to emphasise this cognitive style as a bias, rather than as a deficit. They state it is not related to a global deficit in executive functioning or perspective taking ability (Happé & Frith, 2006).

These differences in cognitive style and the attention to detail associated with this, may be experienced by individuals with ASC as an advantage in some areas (Clarke & van Amerom, 2008; Punshon, Skirrow & Murphy, 2009). For example,

local processing (Happé, 1996) lends itself well to highly detailed, process orientated work, such as programming computer code (Berney, 2004).

'Weak central coherence' (Happé, 1996) is similar to the Relational Frame Theory (Hayes, Barnes-Holmes & Roche, 2001) and LUT learning (Qian & Lipkin, 2011) accounts of an ASC cognitive style (for further detail, see extended paper, section 4.1.6.). Each of these theories accounts for the same symptomatology, from differing theoretical perspectives and using different language. Many individuals with ASC view associated symptoms, or 'difficulties,' as resulting from the reactions of others, rather than from the condition itself (Clarke & van Amerom, 2008; Hurlbutt & Chalmers, 2002), further promoting the concept of ASC as a difference, rather than a deficit.

4.1.8. Autism and mental health

Individuals with ASC may express awareness of how autism can negatively impact upon their experience of their environment, education provision and employment (Hurlbutt & Chalmers, 2002), contributing to a decreased quality of life and increased risk of developing mental health difficulties (Jennes-Coussens, Magill-Evans & Koning, 2006). Barnard et al. (2001) report that 32% of parents of individuals with ASC believe their child to have experienced mental ill-health. Balfe and Tantam (2010) state that many individuals report depression and anxiety, bullying is often implicated and 15% attempt suicide. Rates of mental health difficulties have been found to increase for those receiving a late diagnosis, with Barnard et al. (2001) reporting 45% for those diagnosed in their 20s and 50% for those diagnosed in their 30s. This highlights the importance of improving diagnostic tools, systems and services to aid in the early diagnosis of ASC, both in terms of emotional cost to the individual and financial cost to the state. Higher functioning individuals with ASC are more likely to be susceptible to distress as a result of their social incapacities than less able individuals as they are more likely to be aware of their difficulties (Howlin, 2000). This is especially noticeable when individuals lose their jobs, frequently experiencing low self-esteem and depression (Howlin, 2000). Conversely, and to the surprise of the authors, Brugha et al. (2011) found no evidence of increased use of mental health services by people

with ASC, amongst their large sample of UK adults. This was likely due to the randomised sampling strategy that targeted the UK population as a whole, rather than individuals involved with services. This suggests that ASC is not in itself a predisposing factor for mental health difficulties, although individuals requiring support may be exposed to increased victimisation and social comparison, potentially implicating poor mental health.

4.1.9. Financial implications of autism in the UK

Knapp, Romeo and Beecham (2007) estimated the cost to society for each adult with ASC in Great Britain to be £90,000 a year. For high functioning individuals with autism, the average lifetime cost to the state is reported as £785,000 and £3,000,000 for lower functioning individuals (Jarbrink & Knapp, 2001). Many of these individuals, especially the higher functioning, are likely to be able to work with appropriate support. Many others may also be working without any support, and potentially without a formal diagnosis, making it difficult to obtain accurate estimate of numbers. Barnard et al. (2001) suggest that 32,000 adults with ASC in the UK are candidates for being supported into employment and independent, saving the government an estimated £25 billion over the lifetime of those individuals. Howlin, Alcock and Burkin (2005) also contend that supported employment schemes are an effective way of reducing the financial costs of autism.

Broach et al. (2003) concluded that the long-term costs of autism could be reduced by immediate investment in appropriate support services. In addition to the potential long-term economic gains, this would also help to promote the rights and dignity of individuals with ASC and decrease the social and emotional costs associated with the current situation. It was hoped that this study would provide valuable service user perspective to help inform how to design and deliver 'appropriate support services', as suggested by Broach et al. (2003).

4.2. Personal perspectives on autism

In order to fully understand how ASC might impact upon an individual's transition to work, it is imperative that we consider how individuals relate and consider themselves in relation to their diagnosis, others with ASC, the neuro-typical population and society as a whole.

4.2.1. Reactions to diagnosis

Mixed feelings about diagnosis have been reported amongst adults with ASC, with some viewing their diagnosis as positive and others negative (Huws & Jones, 2008; Punshon et al., 2009; Sperry & Mesibov, 2005). Diagnosis tends to be viewed positively when it is considered to provide access to vocational and ASC specific support (Huws & Jones, 2008; Punshon et al., 2009; Sperry & Mesibov, 2005). Also, it is often seen as providing answers, contributing to self-understanding and a feeling of not being alone; that there are other similar people with similar difficulties (Hurlbutt & Chalmers, 2002). Negative views tend to be focussed on issues such as fear of being stigmatised, or stereotyped as a failure (Sperry & Mesibov, 2005). The impact of diagnosis on an individual's self-concept and social identity, as well as the potential for stigmatisation are considered below (see section 4.4.4.).

A number of psychological models have been applied to the experience of receiving a diagnosis. However, these have only been applied in the physical health field, to diagnoses such as diabetes and HIV, and tended to focus on negative factors and somewhat neglect the positive experiences that might be associated with an ASC diagnosis (Punshon et al., 2009). The Kubler-Ross (1970) model of grief would suggest that on receiving a diagnosis an individual may pass through specified stages of denial, anger, bargaining, depression and acceptance. Later, shock, pain and hope were added to this sequence (Punshon et al., 2009).

Lazarus and Folkman's (1984) transactional model could also be applied to the phenomenon of receiving a diagnosis and adds a more multi-dimensional and environmental perspective, compared to the linear and person specific Kubler-Ross (1970) model. It suggests that an individual's heightened level of stress in

response to a stressor results from an imbalance between their demands and resources (Lazaus & Folkman, 1984). This focus on an individual's interaction with their environment highlights the potential for intervention to reduce an individual's stress response to diagnosis by increasing their resources. This is discussed below in relation to support strategies (see section 4.5.5.).

The cognitive adaptation model (Taylor, 1983) would suggest that on receiving a diagnosis, an individual would instigate three processes comprising of a search for meaning and justification, attempts to gain control and the promotion of self-esteem through comparison to others perceived to be worse-off or 'below' them. This final process of downward comparison may contribute to the 'in-group' and 'out-group' (Tajfel & Turner, 1986) behaviours discussed below (see section 4.2.3.).

Peel, Parry, Douglas & Lawton (2004) report that in their small sample qualitative study, individuals reported three 'routes' following diagnosis of diabetes, which were contingent on their level of preparedness. Individuals who had suspected their diagnosis prior to being diagnosed were less likely to experience shock. This is congruent with Nicholson's (1990) model of transition which highlights the need to 'Prepare' as the first essential stage in a transition process (see section 4.4.1.) Individuals who had experienced symptoms, but were unaware of the reasons for this, often experienced relief following diagnosis and individuals who were not aware of symptoms prior to their diagnosis varied in their reaction (Peel et al., 2004). Punshon et al. (2009) highlight that individuals with ASC will have experienced symptoms throughout their life, but potentially have no insight into the causes of them, particularly if diagnosed later in adult life, as is common for higher functioning individuals with ASC (Barnard et al., 2001). Also, there is no treatment or 'cure' for ASC and it is not progressive, so the notion of 'prognosis' is fundamentally different from the physical illnesses to which these psychological models have been applied. Punshon et al. (2009) reported on the diagnosis experiences of 10 adult individuals with Asperger's (high-functioning ASC) using an interpretive phenomenological analysis (IPA) methodology. They reported that participants' experiences of diagnosis were often complex and influenced by

numerous contributing factors, but also that the 'route' individuals took to diagnosis was perceived to be just as important as the diagnosis itself, implicating the utility of the Peel et al. (2004) findings when considering individuals with ASC.

Punshon et al. (2009) reported that some individuals experienced having a diagnostic label as acknowledgement that others have similar experiences and this can help them develop an enormous sense of 'belonging'. They also recommend that individuals should be supported to work through what their diagnosis means to them, with their carers, families and appropriately qualified professionals. Punshon et al. (2009) highlight the importance of social comparisons in developing acceptance or pride following an ASC diagnosis and suggest promoting social networks as these are likely to be of significant benefit (see section 5.5.1.).

4.2.2. Autism and labelling

This study makes reference to autism, autistic disorder, Asperger's disorder, Asperger's syndrome, autism spectrum disorder (ASD) and Asperger's spectrum conditions (ASC). Autism spectrum conditions may be perceived as a less stigmatising term as it does not consider autism to be a 'disorder' and is the preferred terminology for many adults on the autistic spectrum (NICE, 2012; DoH, 2010a). Many individuals with autism acknowledge their difference from the neuro-typical majority population, but do not perceive this difference to constitute a disorder (NICE, 2012). 'Autism spectrum condition' is also the terminology used in the recent Autism Strategy (DoH, 2010a) and as such, this study will use this terminology whenever appropriate. However, participant interview excerpts relating to diagnosis or understanding of ASC will be reported verbatim and the term 'autism' may be used as a short hand reference to this term to facilitate reading and flow of this manuscript. 'Asperger's', when used, refers to individual with an ASC without a learning disability (IQ ≥ 70). For the purposes of this study, all terms listed above are considered to relate to and describe the cluster of symptoms described in the upcoming DSM-V (APA, 2010) as 'Autism spectrum disorders', whilst acknowledging that these will manifest in different individuals to varying extents and therefore present as a spectrum of presentations and impairments.

Kaplan (2000) comments on the difficulties associated with terminology around 'disability' labelling and highlights that a specific difficulty with spectrum conditions such as autism is where to draw the arbitrary line between 'ability' and 'disability', and the stigmatising effect of this. The dominance of the medical model over the last century has fostered the development of the disability and rehabilitation models in healthcare settings, where the 'disability' in conceptualised as a deficit in the individual, rather than an interaction between the individual and their environment (Kaplan, 2000). Kaplan (2000) states that environmental and systemic factors can be just as implicated in the observed functional impairments for an individual (Kaplan, 2000). Kaplan (2000) suggests that the use of terms such as 'condition' and 'impairment' facilitate the consideration of environmental factors more so than 'disability' and 'deficit', which would tend to be perceived as more implicating of individual factors.

Throughout this study the term 'high-functioning' is used with reference to individuals with ASC without a learning disability (IQ ≤ 70) (APA, 2000). A note of caution is required when considering this terminology, as although an individual without a learning disability might legitimately be considered to be cognitively higher functioning that another with a lower IQ, their social functioning may be just as, or even more impaired. Therefore, 'higher-functioning' ASC refers only to more cognitively able individuals and does not reference social functioning or occupational functioning in any way.

Individuals with ASC often express concerns around being labelled, for fear that people will make assumptions on the basis of their diagnosis, rather than viewing them as an individual person; desiring that people will get to understand them rather than their diagnostic label (Punshon et al, 2009; Sperry & Mesibov, 2005). However, many also recognise that labelling is helpful in terms of gaining access to services and receiving support (Punshon et al., 2009; Sperry & Mesibov, 2005). Huws and Jones (2008) report that some participants felt that a label helped to reduce negative treatment from others.

In the context of transition to work, deciding whether to disclose an ASC diagnosis to a potential employer is a key issue for many individuals in transition and support in making this decision is often required (Ardreon & Durocher, 2007).

4.2.3. Autism and identity

Identity has been defined as 'the way a person understands and views himself, and is often viewed by others' (Holland, Lachicotte, Skinner & Cain, 1998). Bagatell (2007) comments that very little has been written about ASC and identity and it has been suggested that people with ASC may even lack a coherent sense of self (McAdams, 1997). Individuals may actively and desperately seek to develop a sense of identity in the social world (Bagatell, 2007), which has been termed 'identity hunger' (Sacks, 1995).

All individuals naturally identify themselves as members of groups within society in order to maximise their distinctiveness, develop identity and promote self-esteem (Tajfel & Turner, 1986). By identifying with specific groups, the opportunity is created for social comparison to other groups and the phenomenon of in-groups and out-groups. This is characterised by the tendency to attribute favourable information to 'in-groups' with which they identify and negative information to 'out-groups' of which they are not members (Tajfel & Turner, 1986). Group identity could be defined as a network of people who co-produce similar discourses, activities and artefacts (Holland et al., 1998). This model does not specifically relate to individuals with ASC, but considering none do, it is worth considering existing theoretical models and their application to transition to work for this population.

In the current social context, many systems naturally create social groups, within which individuals may share common identities. For example, diagnostic systems such as the DSM-IV-TR (APA, 2000) and ICD-10 (WHO, 1992) create initial social labels for disabilities or conditions, including ASC, which are further propagated and reinforced by services supporting these individuals. Shakespeare (1996) reflects on how identity can be shaped and constrained by institutions such as these, but also how when identity is constrained in this way, individuals often

create a more positive identity related to their disability, in which they resist the dominant discourse and form communities and groups where the concepts of their disability are perceived in a different way. Shakespeare (1996) highlighted that the formation of an identity involves a complex interaction of political, cultural and personal factors.

Many individuals with ASC identify strongly with other individuals with ASC as a group. This is perhaps most noticeable amongst people diagnosed with Asperger's syndrome, who often readily identify themselves as 'Aspies'. Groups such as Aspies for Freedom (2012) actively promote the rights of individuals with ASC, organising events such as 'Autistic Pride' and lobbying against genetic testing for ASC and the search for a cure, as being an 'Aspie' is not considered as relating to being disabled amongst this group. Ward and Myer (1999) comment on how the use of computers has increased communication between people with high-functioning ASC and facilitated the development of an 'Aspie World' and identity. These factors facilitate the provision of self-advocacy and self-support groups within these communities (Bagatell, 2007) (see section 4.5.1.), but are perhaps surprising given the social difficulties associated with the condition (APA, 2010). This highlights the importance of social identity (Holland et al., 1998) and belonging (Sherbourne & Stewart, 1991) to individuals with ASC, which are important factors to consider in relation to seeking employment in a work culture dominated by neuro-typicals.

Bagatell (2007) reports an ethnographic case study of an individual with ASC, called Ben, who struggled to develop a sense of identity. It is reported that Ben had felt 'different' for most of his life and experienced depression as a result of this. Ben experienced relief from this and developed an improved sense of self, after discovering 'the Aspie world'. Bagatell (2007) also highlights how the 'Aspie World' often finds itself in conflict with the pressure for 'normalisation' from the neuro-typical world. Prejudices against 'out-groups' (Tajfel & Turner, 1986) often surface in situations such as this, as illustrated by 'neuro-typicals', or 'NTs', sometimes being referred to rather derogatorily on Aspie web forums, just as Aspies often face stigmatisation in everyday society (Bagatell, 2007).

Many individuals with ASC report feeling isolated, wishing to be more fully integrated with 'normal' society and frequently report feeling stigmatised (Clarke & van Amerom, 2008; Hurlbutt & Chalmers, 2002). Sperry and Mesibov (2005) suggested that individuals with ASC often wish to be treated like a 'normal' person in the workplace, following their qualitative investigation into personal perspectives within peer support groups for ASC. This suggests that these social and identity issues also pervade work environments and may require close consideration in transition planning.

Asperger's, referring to higher functioning ASC, is often described as a 'hidden disability', not only because it is impossible to tell from someone's appearance that they have an ASC, but also because people with ASC are often marginalised, on the edge of society and out of sight (Hill, Dockery, Perkins & McIntosh, 2011).

4.3. Autism and work

4.3.1. Work and its psychological costs

Unemployment can be harmful to both psychological and physical health. It is associated with higher mortality, poorer general health, increased illness and health care costs, mental health difficulties and psychological distress (DoH, 2005). The unemployed are twice as likely as those employed to experience depression, anxiety, psychosomatic symptoms, tiredness and poor self-esteem (Paul & Moser, 2009; Price, 2011).

For those who are employed, Price (2011) states these issues can be precipitated by limited control over work, leading to poor life-satisfaction. This may relate to the concept of self-determinism (Gagne & Deci, 2005) and its impact on self-concept and emotional well-being (for further detail, see extended paper, section 4.4.3.). Unemployed individuals often also report a poor sense of social belonging (Steward et al., 2009). Financial implications of being unemployed further compound these problems, as the ability to pay for daily activities is limited, potentially leading to increased social isolation and boredom (Price, 2011). Low social support and fewer financial resources are associated with lower emotional well-being (Creed & Watson, 2003). Although this evidence does not specifically relate to people with ASC, it may well be relevant to consider in terms of how it does apply to individuals with ASC in the UK, as they transition to employment.

4.3.2. Psychological benefits of work

In a systematic review of the literature, Waddell and Burton (2006) state that although long-term costs of unemployment are widely acknowledged to adversely impact on physical and mental health, the opposite assumption that employment has a positive impact on these factors, is not necessarily true. Evidence highlights potential psychological benefits from employment, only given appropriate employment characteristics (Waddell & Burton, 2006).

Increasing employment is central to recent UK government social and economic policy, with documents such as the Health, Work and Well-Being Strategy (DoH,

2005) aimed at reducing social care and health costs, as well as promoting the economic, health and psychological benefits at the individual level. The DoH (2005) suggests employment is an important method of securing economic resources essential for participation in society and material well-being. The psychological benefits of employment include meeting social needs such as companionship and group cohesion, as well as developing a sense of belonging (Price, 2011).

Work plays a key role in meeting important psychosocial needs in individuals in societies where employment is the norm, as conformity to perceived social norms is related to increased positive emotions (Christensen, Rothgerber, Wood & Matz, 2004). Xanthopoulou, Bakker, Demerouti and Schaufeli (2009) highlight that work can lead to feelings of self-fulfilment and the development of personal resources. Boardman, Grove, Perkins and Shepherd (2003) stipulate that the 'latent', non-financial benefits of work include the development of social identity and status, social contacts and support, as well as structured activity and a sense of personal achievement. Work is thought to be central to individual identity, social roles and social status, with employment and socio-economic status being the main drivers of social gradients in physical and mental health and mortality (DoH, 2005).

Emotional well-being is also associated with increased productivity in the work place (Harter, Schmidt, & Keyes, 2003), illustrating the potential for mutually beneficial relationships between employee and employer. 'Positive psychology' promotes that providing a safe and enjoyable work environment leads to employee well-being and productivity (Harter, Schmidt & Keyes, 2003). Price (2011) highlights the importance of employee control, as well as the availability of resources as the principle factors in ensuring positive psychological benefits of work are realised.

The Demand Control Model (Karasek, 1998) emphasises how high demand on employees, combined with high employee control and autonomy in the workplace promotes employee skill acquisition and mastery. Beehr (1976) also demonstrated increased role autonomy promotes life and job satisfaction, mood and self-esteem.

This parallels how high employee self-determinism (Gagne & Deci, 2005) (see section 4.4.3.) may develop employee personal resources, satisfaction and emotional well-being. Karasek (1998) states that, in order for employees to thrive in a high demand environment, there must also be a context of high support, with quality interactions between all staff and managers, in order to prevent psychological burnout and emotional exhaustion. The Job Demands-Resources Model (Bakker & Demerouti, 2007) further explicates 'resources', to include physical, social, organisational and psychological factors. Bekker and Demerouti (2007) define job 'demands' to be any activity requiring sustained psychological or physical effort, with associated potential costs if they excessively exceed resources.

Variations in the balance between demands and resources will inevitably vary the psychological benefits an individual gains from employment. Waddell and Burton (2006) highlight that a minority of individuals may experience adverse impact on health and well-being from employment, associated with the physical and psychosocial characteristics of individual jobs. However, insufficient evidence exists to identify which characteristics might be most harmful, or beneficial (Waddell & Burton, 2006).

In a longitudinal study in Australia, Butterworth et al. (2011) found individuals who entered jobs 'of poor psychosocial quality', taking into account level of control, demands and complexity, job insecurity and pay, experienced a greater decrease in mental health than the improvements experienced by those moving into jobs of high psychosocial quality, as measured by the Mental Health Inventory (MHI-5) (Rumpf, Meyer, Hapke & John, 2001). However, the DoH (2005) maintains that, generally, the beneficial effects of employment outweigh the risks.

Considering the physical and psychological impact of differing employment settings on individuals with ASC transitioning into employment, the importance of appropriate job matching and individual skills assessment, as recommended by NICE (2012), is highlighted (see section 4.5.). However, as with the majority of employment and organisational research, the research presented relates to the neurotypical population and may not generalise to individuals with ASC. Some

evidence indicating potential benefits of employment to individuals with ASC is discussed below (see section 4.3.3..).

4.3.3. Autism and employment factors

People with ASC often find it difficult to attain and maintain employment, even if they have average or above average cognitive functioning (Barnard et al., 2001). Considering a review of the literature (Higgins, Koch, Boughfman & Vierstra, 2008) and six individual experiences of work (Hurlbutt & Chalmers, 2004), this is most likely due to the impairments in communication and social functioning, rather than difficulties with the requirements of the role. Poor social skills have been found to be associated with poor employment success (Chadsey-Rusch, 1992). Barnard et al. (2001) report that 10% of adult individuals with ASC in the UK are in employment, with around 6% working full-time and 4% part-time. They report 24% 'do nothing' or are 'helping out around the house'. In their longitudinal study, Howlin, Goode, Hutton and Rutter (2004) state that, at follow-up in adulthood (mean age = 29, range 21-48), only 13% of their UK sample of 68 were in competitive employment and 18% were employed in a sheltered or supported setting. Similarly low rates have been reported in the USA (Ballaban-Gil, Rapin, Tuchman & Shinnar, 1996) and Canada (Eaves & Ho, 2008), suggesting that poor employment is a common phenomenon for individuals with ASC across the world.

A survey in the UK (Barnard et al., 2001) estimated the total number of adults in the country with high functioning autism or Asperger's syndrome as 160,100. Of those that were unemployed, 80% reported that they desired paid employment. A National Autistic Society (NAS) report (Hill et al., 2011) suggests the majority are keen and capable of work, but does not report where this judgement comes from, highlighting the need for research incorporating individual perspectives in the field.

Despite their high level of unemployment, individuals with ASC can be successful in many different types of employment, whether supported, or competitive (Shepherd, 2004). Hillier, Campbell et al. (2007) state that individuals with ASC can be successful in competitive employment and are frequently rated highly by employers; seven out of a sample of nine had successfully maintained

employment over two years. They are often perceived as good time keepers and able to get on with repetitive work others may find aversive, without getting distracted by office politics or gossip (Berney, 2004), although some of these statements appear to be based on anecdotal evidence or expert opinion, rather than in-depth investigation.

On average, individuals with ASC tend to work longer hours when competitively employed, compared to when in supported employment. Job retention was lower in the competitive group and provider costs significantly greater due to the complex needs of these individuals (Ozonoff, Rogers & Hendron, 2003). Research investigating individual experiences may indicate areas for intervention around these complex needs and offer opportunity for improving job retention in this population.

Older individuals with ASC are more likely to be employed, compared to their younger counterparts. This is likely due to increased education, work experience and life experience in this group (Schaller & Yang, 2005). This perhaps relates to increased exposure and learning opportunities within the context of a neuro-typical society. Turner (1999) highlights that there is good evidence that social and communication skills improve with age in individuals with ASC, but any relationship between age and repetitive behaviour remains unclear.

For individuals with ASC, difficulties with employment extend beyond finding a job in the first instance (Berney, 2004). Barnhill (2007) conducted a review of the literature on adult outcomes for individuals with ASC and identified that employment is often not suitably matched to individuals' ability levels. Those in paid employment often report that their job roles are below their level of ability and poorly paid (Hurlbutt & Chalmers, 2002; Jennes-Coussens et al., 2006). Mark Romoser, a high functioning man with ASC in the US, has coined the term 'mal-employment' (2000) to describe working far below your skill level and at a task for which you are unsuited, suggesting that this is common for many adults with ASC. Many individuals with ASC who are employed report that they are disappointed by their occupational level and status (Barnhill, 2007).

Berney (2004) suggests that for individuals with ASC, difficulty finding employment begins with the skills necessary to be successful at a job interview. Barnhill (2007) highlights that individuals may possess the technical skills required for a job, but are unable to engage in the conversational reciprocity and quick thinking necessary, or respond swiftly to interview questions. No studies have been identified which incorporate individual perspectives on job interview processes, which neglects an important source of information concerning how best to support people with ASC around this process.

In her review of adult outcomes for ASC, Howlin (2000) suggests that individuals who do successfully attain employment, often lose jobs prematurely. They have difficulty adjusting to each new job setting as a result of their rigidity and preferences for routine and generally earn lower wages than their typically developing peers (Howlin, 2000; Jennes-Coussens et al., 2006). This is also supported from the perspective of individuals with ASC in employment (Hurlbutt & Chalmers, 2004). Berney (2004) suggests difficulties in work may be experienced around social interactions, unexpected events and deviation from routines. From the perspective of employed individuals with ASC, social communication difficulties with employers and co-workers, social skill deficits and sensory issues were reported to have the largest impact on maintaining employment (Hurlbutt & Chalmers, 2004). Victimisation of individuals with ASC in the workplace is also a commonly reported problem, especially for higher functioning individuals who may be more aware of their difficulties and more sensitive to this (NICE, 2012; Hurlbutt & Chalmers, 2002; Punshon et al., 2009). Individuals may even struggle in jobs which capitalise on their special interests or methodical approach if they become bogged down in ritual slowness or their special interest takes over (Berney, 2004).

Successful posts are characterised by in-built support to identify problems as early as possible so they can be quickly detected and rectified (Berney, 2004). A dedicated individual, such as a job coach, would be well placed to offer such support, but success at work will also depend on the support that the employer and colleagues at work are able to provide (Berney, 2004). This is a support

measure which has also been experienced positively by individuals with ASC in work (Hulbutt & Chalmers, 2004).

Although limited, there is some evidence of the benefits of employment for individuals with ASC. Supported employment has been found to lead to improvements in cognitive functioning among individuals with ASC (García-Villamisar & Hughes, 2007). Paid inclusive employment has also been found to have a positive impact on the quality of life and self-esteem for individuals with intellectual disabilities (Eggleton, Robertson, Ryan & Kober, 1999), which most likely would also apply to individuals with ASC, given the positive experiences of work expressed by individuals with ASC in Hurlbutt and Chalmers (2004) qualitative study. Further qualitative enquiry may indicate of how better to support individuals with ASC to more positive experiences of employment.

4.3.4. Autism, employment and UK policy

In a report for the National Autistic Society (NAS) Prospects service, Hill et al. (2011) highlight how "disability and equality laws, as well as Health and Safety legislation, place a duty of care on employers to make reasonable adjustments for their disabled employees". ASC is considered a disability under both the Disability Discrimination Act (2005) and the Equality Act (2010). Human resources and occupational health departments are required to guarantee that appropriate supports are in place to ensure that those with ASC do not face barriers to employment success (Hill et al., 2011).

The UK government has recently published the Autism Act (2009) and Autism Strategy (DoH, 2010a) which specifically make provisions to help promote the government's vision is that 'all adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them.' This means that local authorities and health bodies now have a statutory responsibility to meet the needs of adults with ASC and are accountable to the Secretary of State for Health (DoH, 2010a)

NICE (2012) guidelines incorporate a specific aim of improving access to services and support for individuals with ASC. Within this document, designed to support clinicians in making decisions on best evidence based practice, supported employment is recommended as a psychosocial intervention for adult individuals with ASC and specific guidelines are provided for how this should be done (see section 4.5.). Person-centred service provision is at the heart of all of these documents and yet service-user perspective is noticeably lacking from the evidence base on which they are based. This study aims to provide a valuable service user perspective on transition to work for individuals with ASC, in the hope that this might facilitate delivery of more person-centred support.

4.4. Transition

Transition could be defined as a "discontinuity in a person's life space" (Adams, Hayes, & Hopson, 1976, p. 5) and is often associated with loss, or change in a person's life roles (Liddle, Carlson & McKenna, 2004). The individual's perception of the transition is instrumental in shaping their experience of it, whether positive or negative (Theorell, 1992) and their subsequent adjustment to it (Parkes, 1971). If a transition is anticipated or chosen then a person is likely to adjust to that transition more readily (Blair, 2000). This is concordant with the psychological models discussed above in relation to 'reactions to diagnosis' (see section 4.2.1.) and suggests that diagnosis represents a transition in itself, from non-ASC to ASC. Self-determination theory would also assume that if a person gains satisfaction intrinsically, from completion of a transition directly, rather than receiving a reward from an external factor such as a boss, then they will be more motivated to complete the transition (Gagne & Deci, 2005). This highlights the importance of individuals being informed, committed and in control of transition processes, whether relating to obtaining a diagnosis or transitioning into an employment setting. Ronka, Oravala and Pulkkinen (2003) highlight that personal choice and decision making have a huge influence on the perceptions and outcomes of transitions.

4.4.1. Models of transition

A number of models have been developed to help understand transitions from the perspective of the individual and facilitate their journey through what can sometimes be a difficult process. Liddle, Carlson and McKenna (2004) report that transition can be developmental, situational, or related to health and illness. Factors such as coping skills, ability to adjust and desire for personal growth may also impact upon the perceived success of transition.

Adams, Hayes and Hopson (1976) developed a linear model of transition and its effect on self-esteem, which is considered to fluctuate during a transition process. The model has been criticised for its linear nature, inflexibility and not necessarily being applicable to all people experiencing transition, despite the defence that all transitions, including positive ones, precipitate stress. It has also proved to be

practically useful in discussing transition processes with the individuals involved (Blair, 2000). According to the model, transition involves immobilisation, minimisation, depression, acceptance and letting go, testing, searching for meaning and then internalisation (Adams et al., 1976). Again, this shows striking similarities to the Kubler-Ross (1970) and Taylor (1983) models of coping and adaptation discussed in relation to receiving a diagnosis (see section 4.2.1.).

The Adams et al., (1976) model would conceptualise transition to work as an unpredictable but voluntary transition process. This model incorporates the perceived control an individual has over the transition as well as their expectations about it. The voluntary nature of the transition is beneficial to the experience, but the unpredictability may create difficulty. Nicholson (1990) proposed a process model of transition, or 'transition cycle'. This emphasises that transition occurs over time and involves strategic changes and adjustment. Four stages of transition are represented cyclically and comprise of 'Preparation' which involves the development of expectations, motives and feelings; 'Encounter' relates to building confidence in coping and sense-making leading to 'Adjustment' characterised by personal change, role development and relationship building, and finally 'Stabilisation' through commitment and effectiveness. The transition cycle is considered in the context of the three principles of recursion, disjunction and interdependence (Nicolson 1990). Recursion assumes that transition involves continuous movement, that all individuals are always involved in one or more transition cycles and that states of readiness must exist for future transitions. Disjunction states that each point of the transition cycle is distinctive in nature and requires particular coping mechanisms. Interdependence acknowledges that changes in each stage of the model influence the next stage.

In the absence of any models of transition developed specifically with individuals with ASC in mind, it may be useful to consider these existing models. Given that individuals with ASC often experience difficulty with transition, and perhaps experience it differently from the neuro-typical populations on which these models have been developed, this should be done with caution. Nicholson's (1990) model of transition will be considered in relation to certain experiences of transition to

work, as this appears to be the most comprehensive and up-to-date theoretical conceptualisation of transition.

Blair (2000) states that in occupational settings when individuals experience transition, they tend to experience an urge to keep active and frantically 'to do'. It is suggested that this protects what is familiar and postpones the need to alter roles and associated occupations, motivated by adherence to routine and desire to protect self-esteem. It seems likely that, given individuals' with ASC tendency to rely on routines and present with rigid and repetitive behaviour (APA, 2010), this method of coping might be more readily employed by individuals with ASC as a method of decreasing their anxiety in transition situations. However, reliance on routine and rigid behaviour patterns are, by their very nature, detrimental to a transition process which is fundamentally a change process requiring adaptation and flexibility.

4.4.2. Behaviour change in transition

Transition, as a change process, fundamentally requires those involved to alter their behaviours. The behavioural rigidity and adherence to routines associated with ASC (APA, 2010) may present transition difficulties for this population. It may therefore be useful to consider how some psychological models of behaviour change might be applied to transition processes involving individuals with ASC.

The Theory of Planned Behaviour (Ajzen, 1991) has been extensively researched with regard to effective behaviour change and may be relevant to considering implementing work behaviours in individuals with ASC as they transition to work. The model highlights the importance of knowledge in behaviour change, in a work context this could be conceptualised as an understanding of the desired work behaviours. Perceived control over one's behaviours is also key to implementing effective behavioural change, much along the same lines as self-determinism (see section 4.4.3.). An individual's perception of the subjective norms has also been shown to influence behaviour change, once again highlighting the importance of the social identity and social group identity dynamics (see section 4.2.3) and combining with an individual's attitude to the behaviour to influence the intention to

perform a desired behaviour and the chances of it being successfully performed (Ajzen, 1991).

Social factors, perceived behavioural control (which might also be considered self-efficacy; see section 4.4.4.) and an individual's motivation have the potential to be influenced and could be targeted for support to facilitate successful transition to work for individuals with ASC. Although, this model should be applied to an ASC population with care, as it was developed on an understanding of neuro-typical behaviour.

The trans-theoretical model of change conceptualises time-related change (or transition) in stages, defined as pre-contemplation, contemplation, preparation, action and maintenance (Prochaska & DiClemente, 1992). When applied to transition to work for people with ASC, this highlights that an individual's involvement in the transition is likely to start well in advance of the actual physical transition into the workplace. This model appears to share considerable overlap with Nicholson's (1990) transition cycle (see section 4.4.1.) However, Nicholson (1990) emphasises that behaviour change is constant in transition and that multiple transitions are likely to be occurring simultaneously for any given individual requiring a constant state of readiness for future transitions. Nicholson (1990) does adhere to the concept of a staged model of change, but states that each point of the transition exerts influence the next stage, which he calls 'disjunction', similar to the trans-theoretical model (Prochaska & DiClemente, 1992).

Considering that all of the models discussed appear to relate to much the same concepts and none are based on individuals with ASC, Nicholson's (1990) transition cycle will be considered in relation to the experiences of transition for people with ASC, as this provides an encapsulation of the majority of the processes described in all of the models above, such as behaviour change, social norms, contemplation and perceived behavioural control.

4.4.3. Transition and self-concept

Much of the research discussed in this paper cites theoretical constructs related to the 'self', without much effort made to operationally define what is meant by this. For example, 'self-esteem' is a commonly used term, attributed to a positive feeling associated with one's view or evaluation of their self-concept (Swann, Chang-Schneider & Larsen McLarty, 2007). The prevalence of poorly defined constructs related to the self throughout the literature, limits its utility. Epstein (1979) contends that a concept of the self does not increase psychological understanding in the way that other theories, such as behaviourism, do. Swann et al. (2007) also highlight the theoretical contention that has surrounded 'self-concept' over the past few decades. They suggest that self concept may be a useful construct, when considered in terms of the attitudes and beliefs it represents for the individual, as this has been shown to predict social outcomes reasonably well (Swann et al., 2007). This might therefore suggest that attitudes, beliefs and perceived self-concepts in adults with ASC may well influence transition to work outcome for these individuals.

Work satisfaction and job performance may be associated with successful, maintained transitions to work for individuals with ASC. In a meta-analysis of factors influencing work satisfaction and job performance in the general population, a number of factors relating to the self, including; self-esteem, generalized self-efficacy and perceived internal locus of control found to be the most highly correlated variables (Judge & Bono, 2001). These may also influence work satisfaction and performance in individuals with ASC, and are therefore important to consider in this study.

Self-efficacy (Bandura, 1997) is conceptualised as an individual's perception of how capable they are of performing certain tasks well. High self-efficacy has been shown to be significantly positively related to work performance (Stajkovic & Lufthans, 1998). Locus of control (Rotter, 1966) can be perceived as being either internal to the self, or external. An individual with an internal locus of control will take more responsibility for their actions and successes will likely be attributed to their self-efficacy, rather than external factors such as others, luck or fate. Failures

will also be attributed internally, which provides the opportunity for feedback to be internalised and for personal development. Those with perceived external loci of control will tend to attribute poor performance as the fault of others or bad luck and not take credit where it's due for their successes, tending to lead towards low self-esteem (Rotter, 1966). Perceived locus of control is context dependent and conceptualised as a spectrum where an individual can shift between external and internal loci (Rotter, 1966).

Self-determination theory states that if an individual experiences feelings of autonomy, competence and relatedness then they are best mobilised to function optimally and grow personally (Gagne & Deci, 2005). This is based on the assumption that humans have an innate tendency to strive towards self-fulfilment and development as long as their basic needs are met and the social environment is nurturing.

All of these theories of 'self' appear inextricably linked and complimentary of each other. Applied to the field of transition to work for people with ASC, they all support that individuals with ASC should be centrally involved in their own transition planning, as suggested by Hendricks and Wehman (2009). According to the available evidence, transition to work is far more likely to be successful if the autonomy, self-efficacy and self-determination of individuals are promoted within the transition process. Considering individuals with ASC are likely to be socially withdrawn, as a result of their communication difficulties, it is important that they are actively consulted and encouraged to participate in their transition planning.

All of the above research has been conducted on neuro-typical populations and may not be directly transferable to individuals with ASC. Muller, Schuler and Yates (2008) highlight that little research has been conducted into how individuals with ASC experience their social worlds and themselves within those worlds. Considering the differences in social communication and understanding between individuals with ASC and neuro-typicals these concepts should be applied with caution. However, a number of best practice suggestions in the field of ASC and transition to work do seem to integrate well with these principles. Consideration

and integration models such as Nicholson's (1990) transition cycle, may add further weight. This also highlights the need for studies such as this which focus on individual experiences and allows individuals with ASC to express their perceptions of themselves, of others and of the organisations with which they are involved. Thus, providing a rich source of data from which to consider how best to support individuals with ASC into work.

4.5. Transition support

The socio-communicative difficulties and inflexible behaviour associated with ASC make transitions to new environments a special challenge for this group (Howlin, 2004). Given the difficulties experienced by individuals with ASC, societal factors and nature of transition, it seems likely that the vast majority of individuals with ASC will require support if they are to obtain and maintain employment in the neuro-typical dominated world. A number of sources of support might be beneficial in this instance and these are reviewed below.

Adult services for people with ASC are generally less well developed than child services, and much of the research in the field has focused on early intervention (Howlin, 2004). True social inclusion will not be possible unless much more attention is paid to developing adult services for individuals with ASC (Howlin, 2004). Much of the research into transition support has been conducted on child populations, in education settings or, as previously discussed (see section 4.4.), in relation to neuro-typical individuals. Although it may be beneficial to consider this evidence base, it should be applied with caution when considering the unique characteristics and needs of adults with ASC transitioning to employment.

In her review, Howlin (2000) states that successful adult outcomes for individuals with ASC rarely come easily and that early diagnosis and wide support networks are needed to facilitate more successful outcomes in adulthood. Individuals with ASC face multiple obstacles in the transition from school to further education, independence or employment (Hendricks & Wehman, 2009). Jennes-Coussens et al. (2006) highlight that transition to adulthood can have an adverse impact on mental health and perceived quality of life for individuals with ASC, as assessed by quantitative self-report measures and consideration of a qualitative data. This highlights the potential clinical implications of poor transition and perhaps suggests that mental health costs may be saved if transition is implemented effectively, as well as highlighting the need for the development of a qualitative database within the field, so as to better understand transition from the perspective of the individuals experiencing it.

4.5.1. Social support

Social support can be conceptualised as feeling as though one is cared for, assisted by others and is part of a supportive network (Sherbourne & Stewart, 1999). Social support can be provided by a variety of sources including family, friends, professionals, colleagues or organisations and is thought to 'buffer' psychological distress to stressful life events, including transition (Cohen & Hoberman, 1983).

Support can be 'emotional', 'tangible' (or 'instrumental'), in the form of 'information and appraisal', or as 'positive social interaction' (Sherbourne & Stewart, 1999). Sherbourne and Stewart (1999) also acknowledge that some models of social support identify how 'self-esteem' support can be provided through favourable comparison of the self to others, however, it was not identified in their factor analysis of chronically ill patients' survey responses. Social support can be measured in relation to how the support is perceived, the actual provision of support, or the extent to which an individual is integrated into a social network (Sherbourne & Stewart, 1999).

Social support and its impact upon the quality of life and transition to work experiences of people with ASC has not been studied (Dalrymple & Ruble, 1996; Jennes-Coussens et al., 2006). However, the level of perceived social support is positively correlated with wellbeing among adults and adolescents with ASC in general, illustrating the importance of providing support to these individuals (Dalrymple & Ruble, 1996). Howlin (2000) suggests that individuals with ASC tend to form social relationships based on their rigid routines and special interests which may limit close friendships and the social support that these provide. In a work environment, this may prevent individuals from interacting with their colleagues and meeting the requirements of the role and potentially attract victimisation. Peer support has been identified as a potential protective factor against mental health difficulties, highlighting the need for workers with ASC to be supported to feel secure and productive in the workplace through support and encouragement from colleagues (Ekas, Lickenbrock & Whitman, 2010).

Jennes-Coussens et al. (2006) state that the majority of individuals with ASC remain heavily dependent on support provided by their families, even in adulthood. Given that individuals with ASC may not form comprehensive social support networks by their own means, further investigation into the experiences of support and identification of effective support strategies is required.

4.5.2. Education support

McEachern and Kenny (2007) suggest transition planning groups in schools and the role of school counsellors may have an important role in facilitating transition from school for individuals with disabilities. They suggest career exploration, confronting barriers to employment, the job search process, selecting post secondary training, and addressing other transition challenges might be beneficial. Although these studies do not relate specifically to people with ASC, the same principles may apply, especially given the similarities to the NICE (2012) guidelines (see section 4.5.4). These suggestions are also congruent with Nicholson's (1990) model of transition and could be seen as helping an individual prepare for transition, increasing the likelihood of its success (see section 4.4.1.).

4.5.3. Adult support services

Based on a study of transition between education settings, providing continuity of support and services is central to successful transition, as is the clear definition of the roles and responsibilities of staff involved in the transition (Forest, Horner, Lewis-Palmer & Todd, 2004). Based on their review, Howlin et al. (2004) state that appropriate support provided beyond school and into adulthood is crucial to positive outcomes for adults with ASC (Howlin et al., 2004).

4.5.4. Supported employment

Secker, Grove and Seebohm, (2001) interviewed 150 mental health service users in the UK and identified that good links between education and employment providers and agencies were cited as essential in successful transition to work for this group. Based on their review of the literature on ASC and transition, Hendricks and Wehman (2009) suggest that to achieve quality supported employment, transition services should be user led, career based, supported by employment

specialists and targeted at school leavers. Barnard et al. (2001) highlight that employment support agency provision is limited across the UK. Lawer, Brusilovskiy, Salzer and Mandell (2009) highlight that, in comparison to other groups with disabilities in the USA, people with ASC demand the most expensive employment support, have the highest unemployment rates, but also are the most likely to be competitively employed. Cimera and Cowan (2009) found that adults with ASC tended to be employed for fewer hours and were lower paid, compared to service users with other disabilities in a vocational rehabilitation program in the USA.

Until recently, specific employment support for people with ASC has been severely limited, even in the USA where services tend to be better funded (Howlin et al., 2005). A number of supported employment schemes have been developed have been developed for people with ASC, most notably a programme run by the National Autistic Society, called 'Prospects'. Prospects is an employment and training service for people with an ASC, aiming to provide people with the same training and employment opportunities as non-disabled people. It is specifically designed for individuals with an ASC and an IQ over 60. Prospects works with the individual, as well as with employers, to support the recruitment, training and retention of staff with ASC. The coverage of prospects services is patchy across the UK, although in some locations Job Centre and Remploy provide some coverage (NAS, 2011).

A pilot study of 'Prospects' (Mawhood & Howlin, 1999) reported significantly higher rates of employment amongst its clients (63%), compared to a control group (25%) who only had access to generic disability employment services. It was found that the jobs held by the experimental group were more appropriate to the client's intellectual capabilities and largely involved administrative or computing work. Despite previous employment difficulties, no one within this group was dismissed from their position during the course of the study and salaries and job satisfaction were reportedly higher than for the controls. Additionally, the involvement Prospects was experienced as very positive by both the employees with ASC and the employers involved in the study (Mawhood & Howlin, 1999).

Prospects has been evaluated over an eight year period by Howlin et al. (2005). They report that over this time approximately 68 percent of Prospects clients found employment in 192 jobs. The majority of these jobs were permanent contracts and involved administrative, technical or computing work. In general, higher ability individuals tended to be more successfully recruited, but a number of lower ability individuals still experienced successful transition to work. Involvement with Prospects was associated with higher salaries for individuals with ASC, meaning higher tax contributions and fewer benefits being claimed by participants. Despite this, Prospects was reported as continuing to incur a financial deficit, although this was reported as continuing to decrease over time (Howlin et al., 2005). High levels of satisfaction with Prospects were reported from clients, employers and support workers. Howlin et al. (2005) reported that the outcome of supported employment programmes is superior to other support options such as sheltered workshops or day services. Supported employment programmes are thought to provide more in financial gains and wider social integration, as well as increased satisfaction and self-esteem for individuals with ASC (Beyer & Kilsby, 1996; McCaughrin, Ellis, Rusch & Heal, 1993; Stevens & Martin, 1999).

There are a number of centres in the UK that deliver the Prospects model of supported employment to individuals with ASC. These all focus on supporting job searching, thorough preparation for employment and then support in the workplace once employment has been attained. Prospects specifically focuses on supporting individuals with ASC to obtain jobs that are appropriate to their intellectual ability and educational background (Mawhood & Howlin, 1999). Barnard et al. (2001) suggest that individuals throughout the UK should be entitled to have access to appropriate employment support programmes and that local authorities should play an integral part in devising strategies and liaising with local employment services, in order to develop appropriate supported employment programmes for people with ASC in their area.

Keel, Mesibov and Woods (1997) report on a supported employment programme using highly structured work environments from Division TEACCH (Treatment and

Education of Autistic and related Communication Handicapped Children and Adults). They report an 89% employment retention rate from a sample of 100 individuals with ASC supported in either individual work placements, dispersed work enclaves or mobile support crew model. Keel et al., (1997) highlight utilizing individual strengths and interests, identifying appropriate jobs and providing extensive long-term support as the most important factors influencing employment success. Visual, social, and organisational supports may help to increase an individual's active participation (Fullerton & Coyne, 1999).

A Canadian randomised control trial (Latimer et al., 2006) of 150 adults with severe mental illness found that an individual placement and support model was more effective than traditional vocational rehabilitation services. The supported employment model showed significant advantages in terms of the percentage of individuals who were able to maintain competitive employment (47% versus 18% in the control group) as well as the number of hours they worked (126 vs. 72) at 12 month follow up. The model used key employment specialists who supported the individuals to find a job matched to their interests and capabilities, obtain that job, maintain employment and recover from job loss when necessary, through identifying what went wrong and supporting in finding new employment (Latimer et al., 2006). Although not directly comparable to individuals with ASC, this study represents a large scale demonstration of the potential large positive effect of individual occupational placement and support. Given the lack of evidence directly relating to ASC and transition to work, it seems sensible to consider such evidence in related fields.

4.5.5. Transition to work support strategies

Hill et al. (2011) created a set of guidelines for the National Autistic Society's (NAS) Prospects service, which supports individuals with ASC in employment, specifically designed to aid in the support of individuals experiencing mental health difficulties whilst in employment. This suggested a number of steps which could be taken to facilitate successful transition to work for individuals with ASC and decrease the probability of failed employment and mental health difficulties (Hill et al., 2011). NICE (2012) suggest best practice guidelines based on this, and

other, evidence and also make specific recommendations on how to support individuals with ASC into work. In contrast to the user-focused ethos of these guidelines and recommendations, service-user perspectives are noticeably lacking from the evidence base on which they are founded. The various recommendations and suggested strategies are discussed below. When applied to psychological theories of transition (see section 4.4.1.) and support (see section 4.5.1.), these recommendations are largely congruent. Although, it must be noted that these are theories based on non-ASC populations and therefore the theoretical support for these strategies is questionable.

Forest et al. (2004) state the aim of transition planning should be to maximise the potential for stressful and difficult shifts between settings to occur successfully and highlight how research needs to be conducted into which specific transition elements lead to a successful transition. They published a transition framework for pre-schoolers with ASC entitled 'Elements of Transition to Kindergarten' which centres on effective planning, key-working, sharing of information, skills and needs assessment and child and carer involvement. This was favourably evaluated in general, but lacked analysis of which specific elements were the most beneficial (Forest et al., 2004). No such framework has been identified for planning transition to work for adult individuals with ASC, although many of the suggestions made by Forest et al. (2004) are similar to those proposed by NICE (2012). The lack of research in this area highlights the need for a more in depth understanding of how best to support individuals with ASC as they transition to work and a greater focus on service user perceptions and experiences.

Hill et al. (2011) advised that individuals with ASC should be considered for a work trial, rather than having to attend a more traditional interview process, or at least be allowed to take an advocate into an interview to help them navigate the social and linguistic nuances of the interview process (Hill et al., 2011). Nice (2012) state that employment programmes need to support individuals with CVs, job applications and preparing for interviews. Services should carefully match the applicant to the job and provide training for the identified work role and work-related behaviours and advice should be given to employers on making

reasonable adjustments to the workplace in order to facilitate the individual's transition to work (NICE, 2012). Once successful at interview, individuals should receive a comprehensive induction to ensure that they feel well supported in their role (Hill et al., 2011). These suggestions could be seen as providing a number of support functions (Sherbourne & Stewart, 1991) and facilitating progression through the stages of the transition cycle (Nicholson (1990) (see section 4.4.1.).

Berney (2004) comments on the confusing nature of support networks that surround people with AS, often dominated by 'disability specialists' with limited knowledge of AS and suggests that a key support individual may be beneficial in this instance. Job coaches should provide individual training and support for individuals with ASC in the workplace, in order to ensure continued job success (NICE, 2012). Job coaches' primary roles should be to train the individual in the skills necessary for the job and then gradually reduce their involvement over time, so as to promote autonomy (Unger, Parent, Gibson, Kane-Johnson & Kregel, 1998). Hill et al. (2011) also suggest that individuals have access to a mentor or buddy. Given the social difficulties that individuals with ASC might experience interacting with numerous individuals, access to a single professional to provide all types of support functions (Sherbourne & Stewart, 1991) is likely to be beneficial.

Congruent with Sherbourne and Stewart's (1991) notion of the information and appraisal function of support (see section 4.5.1.), and the Winter-Messiers et al. (2007) strength-based model of ASC, NICE (2012) suggest placing an emphasis on individual strengths and interests when identifying appropriate work experience and employment for people with ASC. The most important factors in ensuring job retention, and 'Stabilisation' of the transition cycle (Nicholson, 1990), through supported employment programmes are appropriate job placement, prior job training, advocacy, follow-up monitoring and long-term support to ensure job retention (Mawhood & Howlin, 1999; NICE, 2012).

Iovannone, Dunlap, Huber and Kincaid (2003) suggest that clear transition goals should be set for individuals with ASC and they should be skills based, functional and developed in a person-centred way, with a view to current and future

placements. Transition goals should address communication and social skills in multiple settings and contexts (Schall & Wehman, 2008) and be directly related to academic goals at school (Downing, 2005). Explicit transition goals should be functional in nature and focus on skills that need to be learnt for current and future environments (Hendricks & Wehman, 2009).

Hendricks and Wehman (2009) highlight the importance of maintaining high expectations for adults with ASC as they move into employment in supporting them to reach their full potential. Transition should be systematically planned well in advance and socially inclusive where possible. In educational transitions, visits to the new site are thought to be beneficial, as is detailed assessment, understanding and sharing of the physical, educational and behavioural needs of the child (Harrower, Fox, Dunlap, & Kincaid, 2000). Nice (2012) also suggests that this support should start before the person starts work and also continue afterwards

Barnard et al. (2001) conducted a study for the NAS on 450 adult individuals with an ASC. They found only 53% had a transition plan in place and only 16% had their identified needs fully met, there also tended to be confusion over which agency was responsible for the welfare of the respondents. 59% of parents felt that responsibility for care and support for their son or daughter with ASC fell between statutory agencies and 66% reported there was no responsible lead agency following a community care assessment of their child. .

Job placements were shown to almost double the chance of successful employment with competitive employment and supported employment rates reported as 84.3% and 82.4% respectively, for individuals with ASC following a job placement (Ozonoff, Rogers & Hendron, 2003). This may relate to the opportunity to learn what is expected in the role, facilitating transition 'Encounter', and practice work behaviours, facilitating 'Adjustment' (Nicholson, 1990).

Support in times of transition may be offered through group format for people with ASC and NICE (2012) suggest that structured teaching techniques should be

utilised to prepare individuals with ASC for employment. Asperger's peer support groups have been reported as helpful by 76.5% of adolescent participants and 95% of their parents (Weidle, Bolme & Britt, 2006). Punshon et al. (2009) highlight that the most appreciated relationships for people with ASC are those formed with other people with ASC, due to the mutual understanding and feeling of 'fitting in', which may add to the benefits of peer support groups during transition. All four functions of support (Sherbourne & Stewart, 1991) could potentially be met utilising group formats (see section 4.5.1.), but little evidence is available on how such groups are experienced, limiting the potential for these to be developed and implemented in a user-informed way.

Hill et al. (2011) suggest that individuals with ASC should have access to anxiety reduction and relaxation techniques during transition to work. Clavenna-Deane (2011) reports on a cognitive behavioural programme which was demonstrated to improve social reciprocity and employment experiences of adults with ASC. Despite the small sample size of four and the need for a greater body of evidence, this perhaps tentatively indicates the utility of such programmes in effective transition. Edelson (1999, cited in Hurlbutt & Chalmers, 2002) suggested that sensory integration training might also be an effective strategy to aid successful transition. If an individual's hyper- or hypo- sensitivity to sensory stimuli can be mediated, then they are less likely to find the workplace an aversive environment.

The most commonly used approach to support individuals with ASC to integrate in neuro-typical society is social skills training (Howlin, 1997; Hurlbutt & Chalmers, 2002). However, no research studies specifically address how individuals with ASC experience their social worlds and which social skills strategies they find most effective in navigating these (Muller et al., 2008). This highlights the predominance of the deficit model of ASC and the notion that individuals with ASC should be 'trained up' in neuro-typical skills so as to fit in with neuro-typical society, rather than celebrate and utilise their neuro-diversity.

The autism strategy (DoH, 2010a) sets out guidance that all transition staff in statutory health and social care services should receive appropriate training about

ASC so they are best placed to help individuals through transition. Hill et al. (2011) state that training on ASC should be provided to line managers and colleagues so that they can provide regular support and monitoring, direct but sensitive feedback, clear and concise non-jargonised instructions and a structured working environment for individuals with ASC (Hill et al., 2011). This highlights the need to consider how organisations, as well as individuals, might also progress through a transition cycle and that actions need to be taken in order to facilitate movement towards transition 'Stabilisation' (Nicholson, 1990).

In their paper exploring life experience perceptions of adults with ASC, Hurlbutt and Chalmers (2002) report that participants felt strongly that "neuro-typicals" needed to be educated about autism. They suggest that support agencies send their staff to ASC training sessions and conferences so they can develop knowledge in the field. They also suggest that staff should be well paid in order that staff turnover might be reduced, as the disruption to routine that this poses for individuals with ASC, as well as the skills loss is detrimental to the transition process (Hurlbutt &Chalmers, 2002). Nesbitt (2000) highlights that organisations are more likely to employ an individual have a greater understanding of ASC and if support is provided by an external agency. Schall and McDonough (2010) highlight the importance of contextual fit between positive behavioural support and the work place requirements in successful employment, as well as effective communication between all stakeholders.

The Autism Strategy (DoH, 2010a) highlights that it is essential that information is communicated between child and adult services when planning transitions for this group. Effective communication ensures that the needs of the individual can be met, but also that services are aware of each others' provision and client numbers, so as to enable better local planning of service provision (DoH, 2010a). Collaboration and communication between individuals, families, caregivers and employers is essential in order to provide effective long-term support (NICE, 2012). However, this is frequently cited as a barrier to successful transition (Schall & McDonough, 2010).

4.5.6. Person-centred planning

Person-centred planning has dominated UK government policy on health and social care for people with ASC since the 'Valuing People' white paper (DoH, 2001). Person-centered care aims to provide service users with more choice over how they live their lives (DoH, 2010a) and enable them to share ordinary places, make choices, grow in relationships, be treated with respect, develop abilities and have a valued social role (O'Brien, 1989). This also pervades the government financial policy in Putting People First (DoH, 2007), which gives service users choice over how they spend their social care funds. Person-centered care is based on a social model of disability which aims to integrate individuals into 'normal' society by supporting them to live with their disability and meet their needs. Person-centred planning has been found to cost about the same as other models of care, but is superior in terms of service user choice and quality of life measures (Sanderson, Thompson & Kilbane, 2006). Person-centred care appears to promote self-determinism (Gagne & Deci, 2005), which may account for such benefits (for further discussion, see extended paper, section 4.4.3.).

The Autism Strategy (DoH, 2010a) states that people with autism, their families and carers, should always be involved in transition planning and the principle of "no decision about me without me" (DoH, 2010b) promoted within healthcare should be applied across transition planning also. The use of advocates is also supported when appropriate, in order to ensure that service user views are heard. Individuals should be actively involved in their own transition planning, ideally taking a leading role, as this provides the opportunity to learn about themselves and plan for their future (Hendricks & Wehman, 2009). Cameto Levine and Wagner (2004) state that less than a third of students with ASC were actively involved in transition planning and only three per cent took a leading role.

4.5.7. Supported employment outcomes

No randomised control trials to support the use of supported employment as an intervention for people with ASC have been identified (NICE, 2012). However, a number of quasi-experimental parallel group controlled trials support that it is an

effective strategy (N=145) (García-Villamisar et al., 2000; García-Villamisar et al., 2002; García-Villamisar & Hughes, 2007; Mawhood & Howlin, 1999)

Supported employment has been shown to be statistically significantly superior to sheltered workshop programmes in reducing measures of 'autistic behaviours' and improving quality of life. Effect sizes were small and moderate, respectively (García-Villamisar et al., 2000; García-Villamisar et al., 2002). Moderate effect sizes have also been shown on two separate measures of executive functioning in individuals with ASC (Cambridge Neuropsychological Tests Automated Battery [CANTAB], 'Stockings of Cambridge' [SOC]) following supported employment (García-Villamisar & Hughes, 2007). However, experimental group sample sizes were not reported, limiting the extent to which these findings can be extrapolated.

Secondary benefits of supported employment are not known, but it is likely that supported employment programmes would precipitate a decrease in the costs to the state of providing social care funded housing and health funded mental health services (NICE, 2012). Curtis (2010) estimated the mean cost of providing supported accommodation to be £64,486 and residential accommodation to be £67,499 per annum. Schneider et al., (2005) report that the average health costs for an unemployed, non ASC, individual are 31% higher than for someone who is employed.

Supported employment as an 'intervention' has been compared to standard care for adults with ASC, in terms of the cost-benefit analysis, measured by NICE in 'Quality Adjusted Life Years (QALY) which are the number of extra years that an individual might be expected to live for each intervention, controlled for by the perceived quality of life during those years (NICE, 2012). NICE consider the cost effectiveness threshold for an intervention to be £20,000 to £30,000 per QALY gained (NICE, 2009). Supported employment was estimated to cost £3,916 per QALY in comparison to standard care, consisting of supported living and day services, which costs £1,581 per QALY. However, supported employment was estimated to provide an additional .20 QALY over standard care. Although more expensive than standard care, the additional cost of providing supported

employment was still only estimated to be £7,657 per QALY gained, which remains below the NICE cost effectiveness threshold.

A secondary analysis was also conducted, which factored in predicted changes in accommodation costs following supported employment, and this reduced the cost of supported employment to £1,739/QALY (NICE, 2012). This was using a very conservative estimate that only 1% of individuals with ASC who attain employment would move into independent living (NICE, 2012). When personal social services costs were also factored in, it was reported that supported employment was almost identical in cost to standard care provision for someone with an ASC at present. Considering QALYs for supported employment are still 0.2 higher, supported employment should be considered the preferred intervention for adults with autism seeking employment (NICE, 2012). The data supporting the economic efficacy of supported employment has been calculated using projections and statistical modelling. Throughout these calculations, conservative estimates have routinely been used to as to not over-estimate the efficacy of this intervention. Despite this, the authors still estimate that there is a 72.2% chance that supported employment will fall below the lower NICE threshold of £20,000 per QALY.

On the basis of recent evidence, NICE (2012) recommend that all adults with ASC who are having difficulty obtaining or maintaining employment, irrespective of their intellectual ability, are considered for an individual supported employment programme. Further evidence from service-user perspectives may shed more light on how supported employment is experienced by people with ASC, offering insight into personal gains, barriers and identifying effective strategies within supported employment.

4.5.8. Future considerations

What has been presented here represents the current state of the evidence relating to transitions to work for individuals with an ASC. What is striking is that guidance relating to how to support these individuals into employment has remained largely unchanged for nearly 30 years. Wehman, Kregel, Barcus and Schalock provided detailed guidance on how best to support adults with ASC into

work in Indiana, in the USA in 1986. This guidance included factors such as a job coach, staff training, involvement of the care network, skills assessment and training, job matching and continuing support to be phased out. All of which sound remarkably familiar, given the current guidance set out by NICE (2012). An advantage of the current drive to support individuals with ASC into employment is that there is an additional 30 years of research now supporting this movement, increased public awareness, increased ease of dissemination and increased efforts to incorporate the views of service users; hence, the efforts of this current study. Howlin (2004) states that expectations for people with disabilities have generally risen over the years. This might represent a cultural change and shift in societal norms, as well as individuals' perceptions of those norms, motivation and perceived loci of control, leading to increased self-determinism and self-efficacy in individuals with ASC over the recent decades. Perhaps this will generate sufficient psycho-social pressure to ensure the current manifestation of guidance on ASC and transition to work will be successfully implemented. Consideration of relevant psychological models such as Nicholson's (1990) transition cycle and Sherbourne and Stewart's (1991) five functions of support may also add weight to the current guidance and help justify some of the specific support strategies suggested. Consideration of individual perspectives is imperative as researchers and practitioners endeavour to develop and deliver continually improved transition to work experiences for individuals with ASC.

5. Extended Methodology

5.1. Additional recruitment information

This study aimed to recruit a relatively small homogenous sample, relevant to the intended area of investigation, as is considered appropriate in qualitative research (Lyons & Coyle, 2007). Guidance on sample size for thematic analyses is non-specific and should be guided by the needs of the study (Braun & Clarke, 2006). Smith and Eatough (2007) suggest an absolute minimum of six participants and Bird (2005) states between eight to 20 is appropriate. A sample size of 10 was aimed for as it was felt that this struck the right balance between an in depth understanding of participant experiences, characteristic of smaller sample sizes in qualitative research and sufficient representation of the target population, whilst minimising the risk of superficial analysis associated with larger scale studies (Boyatzis, 1998). Participants were recruited using a purposive, stratified sampling strategy (Robson, 2002) to identify 10 participants meeting the inclusion criteria of the study. Participants were required to be 18 years old or older and capable of providing informed consent. They must also have been diagnosed with an ASC and have experienced a transition to work that they were able to recall. Agencies responsible for supporting these participants were asked to verify their ASC diagnosis, age and ability to consent. The researcher who conducted the interviews was also a Trainee Clinical Psychologist, who had received training on the Mental Capacity Act (2005). A lack of capacity to consent to participation or risk issues identified by the researcher, participant or agency would have led to potential participants being excluded from the study. No participants were excluded over the course of this study.

Local managers of support agencies involved in supporting individuals with ASC into employment were approached, the purpose of this study was discussed with them and they were asked if they would be willing and able to support with recruitment for the study. Seven different agencies were initially approached and an advert for participants was also placed on the NAS website (appendix 11). All of the seven agencies expressed an interest in the study and a willingness to help with recruitment, but only three of these were sufficiently proactive to distribute the

participant information pack (appendices 2 & 3) to suitable participants and manage responses in order to recruit within the timescale of the study. Participants either stated their interest to the manager that approached them or using the contact details of the researcher provided on the participant information sheet (appendix 2). The participant information sheet provided a brief description of the study and its aims, as well as an expression of interest form (appendix 3).

One limitation of this study might be that supporting agencies were less likely to approach individuals who were less able or less successful in transition to work. An atmosphere of protectiveness was observable within the majority of the services approached and a notion of not wanting to 'rock the boat' with more vulnerable service users. This may have created a more positive set of experiences being reported amongst the recruited sample than might be typically expected from adults with ASC transitioning to work. However, as this study does not purport to provide a representative view of transition to work in adults with ASC, this does not represent a serious methodological issue.

Interested participants either contacted the researcher or liaised through their support agency to arrange a discussion with the researcher using their preferred method of communication, as stated on the expression of interest form (appendix 3) to clarify any questions and arrange the interview. One participant was recruited through the advert placed on the NAS website (appendix 11). A total of eight were recruited through three local support agencies; four from one agency, three and one from the other two. The final participant contacted the researcher after they had developed an interest in participating following a discussion with another participant. Overall, the ten experiences of transition which contribute to this study relate to eight males and two females between the ages of 20 and 49, across four different localities comprising of three different cities and a rural town in the north of England. The researcher was able to identify that participants had been supported by five separate voluntary or private sector agencies between them, in addition to the support received from statutory health and social care services which all participants had accessed. Three of these were ASC specific services, two of which were specifically designed to support individuals with ASC to find and

maintain employment. The other two were enterprises concerned with supporting individuals with mental health difficulties. A number of participants had experienced support provided by at least one of these agencies, allowing for interesting comparisons. Three of the participants were unemployed at the time of the study, six were in paid employment and one was working voluntarily, so as not to affect his benefits, having been in paid employment previously. Two of the participants in paid employment also worked voluntarily. Eight out of the 10 participants identified with the diagnosis of Asperger's syndrome, whilst two reported they had 'autism'. Table 1. provides an overview of the participant descriptive data (see journal paper, section 3.3.).

Interviews were conducted at a time and place convenient to the participants, after informed consent had been obtained using the participant consent form (appendix 4). All of the participants were interviewed either at their home, at their place of work or at their supporting agency's premises. Each participant was interviewed once, interviews ranged from 21 to 101 minutes, with a mean duration of 40 minutes. Interview length was determined by the participant having said all they wished to say and the interviewer having asked all that they felt was relevant to the study, as is suitable for thematic analysis research (Boyatzis, 1998; Braun & Clarke, 2006). It was made explicitly clear that no therapeutic work was intended to take place during the interviews and that they were solely for research purposes. Interviews were only conducted in locations where confidentiality could be maintained and recorded on a digital audio recorder. Participants were given a £10 high street voucher on completion of the interview, in recognition of their time commitment.

Before each interview, the researcher went over the participant information sheet (appendix 2) with each participant to remind them of the requirements of the study and give them the opportunity to ask any final questions. Participants were required to sign a consent form (appendix 4) stating that they had read and understood all the requirements of the study and wished to participate. The consent form explicitly stated that any information relating to potential risk of harm to the participant or to others would need to be shared with appropriate agencies,

in-line with safeguarding procedures. The participant's right to stop taking part in the research up to a week after the interview was reiterated before the interview began. No participants chose to withdraw from this study.

5.2. Interview development

The interview was intended to facilitate participants to reflect on their experiences of transition to work and was therefore exploratory in nature. A semi-structured format was developed, through clinical experience of this population, in order to prompt individuals to recall both negative and positive features of their transition, whilst not leading in any other way. Semi-structured interviews offer structure, whilst also being flexible enough to allow for unanticipated ideas to emerge (Robson, 2002). The interview schedule (appendix 7) was developed in consultation with the second author, who is a researcher experienced in using thematic analysis methodology applied to interview transcripts. During interviews, participants directed the content and direction of the interview. However, as with any didactic relationship, it would be naive to assume that the researcher had no influence over the topics of conversation, especially with less verbal participants. A reflective log (appendix 10) was kept in order that issues of researcher bias or influence on the interview process could be acknowledged and addressed if necessary (Robson, 2002).

5.3. Further ethical considerations

Ethical approval for this study was obtained from the University of Lincoln ethics committee (appendix 1).

Contingency was built into the design of the study to allow for the potential for participants to become distressed during the interview. All participants were made aware of their right to stop the interview altogether, or to have a break from the interview and resume when they felt able to do so. The researcher was a Trainee Clinical Psychologist with experience of responding to people in distress and knowledge of safeguarding issues. Any decision to contact the supporting agency would have been made on a case-by-case basis, depending on the specifics of the situation and, where appropriate, in consultation with the research supervisor. Any contact with the support agency would have been discussed in advance with the participant whenever possible.

Immediately after the interview, when the digital recorder had been switched off, participants were offered the opportunity to debrief, discuss their experience of the interview and ask any questions. They were also offered the opportunity to request a summary report, or the full report of the study if they wished (appendix 5). Interviews were conducted with interest and enthusiasm, in a relaxed, respectful and empathetic style. This aimed to ensure that the participant was satisfied they had said all they wished to say and that they felt treated with respect.

5.4. Data Management

All personal identifiable information was anonymised. Participants were assigned a pseudonym of the same gender that was coded against their true identity and held electronically on a secure server at the University of Lincoln. Participants' ages have been reported unchanged as this adds perspective to the data provided.

All published excerpts from the interview transcripts have been made anonymous and do not contain any identifiable information. Quotations have been checked with participants where possible, via email or phone according to participant preference, to ensure that they have been used in context and accurately represent their views. Participants were made aware before signing the consent form that the interviews would be 'typed-up' by a third party, also bound by confidentiality (appendix 6), both verbally and by way of the participant information sheet (appendix 2). The Dictaphone and consent form were kept in a locked bag whilst in transit between sites, stored in the boot when in motor transit, and transferred onto secure electronic storage, such as the University of Lincoln server or an encrypted data stick at the earliest opportunity. Paper records were stored in a locked filing cabinet in locked facilities at the University of Lincoln for a period seven years, following which they will be shredded. Electronic records will also be deleted at this time. Identifiable data has been stored separately from anonymised data, both in sealed envelopes.

5.5. Further epistemological considerations

Critical realism is consistent with a thematic analytic approach, which is not intrinsically related to any distinct epistemological position (Braun & Clarke, 2006). Critical realism is sympathetic to both the traditional positivist ideology of traditional science as well as the constructivist views of post-positivism (Robson, 2002). Critical realism holds that knowledge or 'truth' can exist and be shared by a number of individuals. However, each individual's experience of truth will be influenced by their own subjective construction of that truth. Truths effectively gain weight, or saliency by accumulating evidence, consistent with Buetow's (2010) conceptualisation of thematic analysis as 'saliency analysis'. The aim of the study is to identify common, as well as conflicting, truths in the experiences of a number of individuals with ASC who have experienced transition to work by focussing on participant responses to open interview questions. The study aimed to provide a rich account of the experience of transition for the individuals interviewed, through inductive, bottom up analysis of participant responses. Analysis was data driven and no attempt was made to analyse the data in accordance to existing theory. Thematic analysis has been criticised for not identifying with any particular epistemological position (Braun & Clarke, 2006). However, Braun and Clarke (2006) suggest that this represents a strength, in that it can be applied more flexibly.

5.6. Further considerations on thematic analysis

It has been proposed that thematic analysis relates to any practice that involves deriving themes from qualitative data (Boyatzis, 1998). This broad definition encapsulates all qualitative research methodologies, and indeed much of human understanding and functioning. To some extent, all social understanding is based on the automatic and instant thematising of the information presented, in the context of past experience and learning. Different qualitative methodologies, in conjunction with an explicit epistemological position, apply 'lenses' through which data is analysed and made sense of. Braun and Clarke (2006) state that thematic analysis specifically relates to the process of identifying, examining and recording patterns in data sets that are related to a specific research question and describe a specific phenomenon.

Thematic analysis was considered to be an appropriate methodology as it allows for the analysis of a large amount of data from multiple participants to be analysed and synthesised into a meaningful account. It provides a structured methodology for identifying key themes within a data set and is not overly constrained by aligning with any one particular epistemological position (Boyatzis, 1998).

The interview transcripts were transcribed by a paid professional transcription service, bound by a confidentiality agreement (appendix 6). Although some authors advocate that researchers should transcribe interviews themselves, so as to facilitate immersion in the data (Pope, Ziebland & Mays, 2000), this was not necessary in this instance. The researcher conducted the interviews himself and had already been exposed to the data once, on receipt of the transcriptions they were also read over and checked, further enveloping the researcher in the data. Additionally, the semantic nature of the data analysis meant that the researcher was not aiming to interpret the participant's experiences, merely to group them thematically according to their semantic meaning, which is well represented in written format. Utilising professional transcription services was an effective use of time and resources, freeing the researcher up to work on other aspects of the study.

The analysis of data was guided by Braun and Clarke's (2006) account of thematic analysis as it was felt these guidelines offer an up to date and practice-based conceptualisation of the method. Buetow's (2010) conceptualisation of thematic analysis as 'saliency analysis' supported in the identification of frequent and salient themes within the data set.

Firstly, the transcripts were read over a number of times to facilitate familiarisation with the data and initial ideas were noted down. Transcripts were then subjected to line-by-line coding of the data (appendix 8). Once these initial units of analysis, or codes, had been identified they were grouped together with other similar codes into potential thematic categories. Themes were continually reviewed until they were judged to be consistent across all participants and at the individual level, supported by quotes and named appropriately (appendix 9). The identified themes

are intended to provide a rich and detailed description of the data set (Braun & Clarke, 2006).

Throughout analysis, at times the researcher felt that coding and thematic grouping was being informed by exposure to previous transcripts and interviews. Pope et al. (2000) state that this continuous and organic analysis is almost inevitable in qualitative research, due to the researcher's continual involvement in data collection and analysis processes. They state that is not possible to exclude what has previously been seen and heard from the analysis, but that this can be a strength, in that the researcher's involvement in these processes is an important source of information.

In order that the most important themes could be appropriately addressed in the context of this study, some themes were considered not appropriate for inclusion. These were identified in accordance with Buetow's (2010) conceptualisation of thematic analysis as saliency analysis. In short, if themes were not sufficiently represented in terms of frequency (number of participants) and saliency (importance) then they were removed from the analysis. Frequency was considered as the number of participants commenting on a specific issue, rather than the frequency of codes related to it, in order to control for perseveration of speech and high levels of repetition amongst some individuals with ASC (Rehfeldt & Chambers, 2003). For the purposes of this study, saliency (Buetow, 2010) was identified by rooting this concept in the participant data. Comments such as "the most important thing in my transition was..." and "it was key"... were taken to represent saliency for that individual. This helped minimise the impact of the researcher's preconceived ideas of importance and knowledge of the evidence base on the analysis. In this study, themes were discarded if they were not supported by saliency statements and related to a frequency less than five. The decisions relating to what constitutes frequency and salience is inherently subjective and researcher influence in this process cannot be avoided. The influence of researcher bias in assigning frequency and saliency to themes is acknowledged throughout the reflective log. Lyons and Coyle (2007) suggest that thematic saturation indicates that an appropriate sample size had been achieved.

This was considered to have occurred in this study as analysis of the last few transcripts did not result in the generation of any new themes within the data set.

The three main themes identified in this study were 'Diagnosis', 'Barriers to transition' and 'Transition support', each with its own sub-themes. Themes were organised into this matrix to generate the theme maps (Fig 1., section 3.4; Fig 2. & Fig 3., section 6.4.). Liddle, Carlson and McKenna (2004) state that using a matrix in transition research helps lead to an enhanced and comprehensive understanding of individuals' experiences. However, little evidence based guidance exists in the use of matrices in qualitative research (Averill, 2002). The development of the thematic matrix in this study was therefore informed by saliency analysis (Buetow, 2010). Themes were discarded if not supported by saliency or frequency, rather than manipulated to fit the thematic matrix.

5.7. Semantic versus latent analysis

This analysis focused on the semantic content of interview transcripts, rather than latent information and the interpretation of meaning. A semantic approach identifies themes within the "explicit and surface meanings of the data and the analyst is not looking for anything beyond what a participant has said or what has been written" (Braun & Clarke, 2006, p. 13). In contrast, a latent approach "starts to identify or examine the underlying ideas, assumptions, and conceptualisations and ideologies that are theorised as shaping or informing the semantic content of the data" (Braun & Clarke, 2006, p. 13). A semantic approach is consistent with a critical realist epistemological position in that it limits over-use of subjective interpretation and focuses on identifying common semantic themes within and between the transcripts.

This study focussed on providing a description of the patterns in semantic information in the data set, and then summarising, interpreting and theorising around the broader meaning and implications of the patterns found. Interpretation often occurs in consideration of previous data and theory (Braun & Clarke, 2006). However, it is key that previous data does not influence the analytic process before hand. In contrast, latent level analysis attempts to identify the underlying

concepts that inform and shape the data throughout analysis. It is concerned with explaining the shape and form of the data, rather than a semantic level description.

This study focussed on a semantic level interpretation primarily because of the intention to represent participant views from a perspective that was congruent with the understanding and views of an ASC population, in respect of their transition to work. The researcher was keen not to infer and impose their own neurotypical understanding and position, laden with their own conceptions and values, informed by their own personal experiences, work history and theoretical interests. For further details see reflective section (extended paper, section 8.2.).

5.8. Inductive versus deductive analysis

This study used an inductive thematic analysis methodology to focus on the semantic information obtained from interviews to investigate the experiences of transition to work for participants with ASC and develop 'bottom-up' themes. Inductive thematic analysis contrasts a deductive, 'top-down' approach, that would typically use a more structured interview format and direct participants to respond to specified topics informed by the existing evidence base (Braun & Clarke, 2006). An advantage of an inductive approach is that it is open to hearing about participants' experiences, rather than seeking their views on topics biased by the evidence base. This helps to avoid assumptions and biases in the literature being perpetuated. Inductive analysis is not driven by the researcher's theoretical interests, or pre-conceived analytical frames (Braun & Clarke, 2006). However, Braun and Clarke (2006) also highlight that researchers can never entirely free themselves from their theoretical and epistemological position. Therefore, this data driven form of analysis, must be considered in light of individual researcher factors.

This study would have benefitted from a more explicit statement relating to the researcher's personal understanding and position on ASC, mental health, employment and transition. For further details see reflective section (extended paper, section 8.2.).

5.9.   Reflections on analysis

From the organisations which supported with recruitment for this study, some appeared to have more effective transition support programmes in place. The researcher tried not to focus on the activity of the organisations as preconceptions would undoubtedly risk influencing questioning during the interviews.

Some support staff from these organisations were concerned that participants would not mention all of the support they received due to their literal understanding when responding to questions. This was also a concern of the researcher and perhaps led to the tendency to ask more questions during the interview than intended by the interview schedule, and therefore will have increased the risk of leading participants and detracting away from their experiences. However, this was necessary, especially given that some of the interviewees lacked the conversation skills to elaborate on certain points, answering very stiltedly, as might be expected from individuals with an ASC diagnosis. Conversely, another characteristic of people with ASC is perseveration of speech (Rehfeldt & Chambers, 2003). This led to a number of participants going into lengthy, repetitive monologues about a specific area. This potentially raised the frequency of certain codes for those participants and therefore raised concerns in terms of how this repetition should be analysed. It was decided to stick rigorously to understanding frequency as the number of participants commenting on a given theme, in order that participants were equally represented, and reflect on this difficulty rather than risk adding a further level of subjective analysis.

5.10. Research design considerations

A follow-up study may have been preferable due to concerns over accurate retrospective recall, but was not possible given the time constraints of the study. However, retrospective recall is not necessarily inaccurate, especially when it is autobiographical and personally salient for the individual (Blane, 1996), as is likely to be the case in individuals with ASC as they transition to work. Other studies have successfully conducted thematic analysis on retrospective interview data with participants with ASC (e.g. Dann, 2011).

Although the main focus of the data collection and analysis was to collect information on participant experiences and report this solely from the perspective of the participants, the researcher's influence on this process cannot be ignored. All researchers had worked with people with ASC and most likely had preconceptions and expectations about what this study was likely to reveal. So as to acknowledge this and reduce the potential for researcher bias to impact the analysis, a reflective log was kept (see appendix 10), as recommended by Robson (2002).

6. Extended Results

Three main themes relating to transition to work were indentified from the data: 'Diagnosis', 'Barriers to transition' and 'Transition support'. These were all considered to be frequent themes within the dataset and highly salient for the majority of the participants. The theme titles do not represent exact participant quotes; they have been assigned by the authors so as to best describe the themes that emerged (Boyatzis, 1998). Although a central theme was not found in this sample, we suggest the tentative statement of "Transition to work can be facilitated by early diagnosis, providing access to appropriate services that offer well planned sustainable support throughout transition, appropriate to the needs and skills of the individual" as a suitable synthesis of the three main themes. 'Transition support' results are presented in the journal paper (see section 3.4.), the other two themes are reported below. An overview and the 'theme maps' (Braun & Clarke, 2006) are presented below (see section 6.4.).

6.1. Diagnosis

All ten participants cited that diagnosis was a key factor in their experiences of transition to employment. Subthemes of 'Access to support', 'Identifying with ASC', 'Other-understanding' and 'Delay in diagnosis' were identified.

Access to support provided by their diagnosis was identified by seven participants as a key factor in their transition. They reported that this provided them with a sense of eligibility and recognition within society. This recognition was also experienced as providing access to state benefits, and formal recognition that they required financial support to fulfil basic human needs:

> With my diagnosis of Asperger's syndrome everything changed, I was now eligible. I was able to get that extra support, so I have been out of the circle of being a statistic on the unemployment thing, to being pushed to the front of the queue. (Brian)

> At least there is recognition, so that's an improvement. And, of course, financially I'm a lot better off, which means I can eat healthily and put my heating on in the winter. (Donald)

Identifying with ASC was highlighted to be relevant to transition to work for eight of the participants interviewed. Strengths which participants associated with ASC were attributed to themselves, following diagnosis. Participants identified that social and communicative features, as well as the rigid and focussed cognitive style characteristic of ASC may benefit work roles:

> Well you get somebody who works rather than gossips and I always used to get in at nine o'clock. I liked the routine. (Donald)

> But the amount of attention to detail and data capture and things that I'll have, will be higher than more or less anyone there. (Elliott)

Following diagnosis, self-understanding and awareness was felt to be improved for three, offering explanations for perceived social and occupational difficulties and thus reducing associated anxiety:

> And it's made me feel, in some ways, less concerned or less worried because it's answered a lot of questions. It's like I'm not just a freak, there's a reason for it, is the sort of feeling I got since my diagnosis. (Elliott)

> [ASC symptoms] can make you totally incompetent in a working or social environment. But at least I'm aware, I'm aware of that now why it happens. (Donald)

Limiting aspects of ASC traits in transition were also identified, these are addressed in 'Barriers to transition' (see section 6.2.).

Other-understanding of ASC was identified by eight participants as impacting on their transition experience. Some participants reported that they experienced diagnostic and support services not to have a good understanding of ASC, in terms of understanding its presentation and course:

> I just hope it would provide better recognition from people in general to recognise that erm… that Autism and Asperger's Syndrome is not to be confused with physical and mental disabilities that happen tempo-… temporarily from… from the DWP [Department of Work and Pensions]. And the main focal points, about erm… would have been this recognition I was talking about, and er… and the… it's to try and… is to try and recognise autism as a permanent disability, and not a temporary one. (Samson)

Participants also highlighted the role of others' understanding in obtaining their diagnosis. This tended to relate to a family member who sought support for observed social difficulties:

> Well my dad noticed that I were shy talking to people I didn't know. I always avoided social situations, things like that, so he wondered… so… I was then tested by a psychiatrist and she diagnosed me with it. (Frank)

Participants also felt that it was beneficial to promote others' understanding of ASC in a work context, in order to generate opportunities for work from employers and facilitate their interactions with work colleagues when in role:

> Make a point to erm... other people to give people with autism a chance for work, and erm… do not judge them by what they have, but to judge them by their personalities, judge them of how they can be hard workers. (Bruce)

> I think they're just aware a bit more of the fact that I might not talk and when I do talk I might, I sometimes might go on a bit. (Elliott)

Some also appeared to view ASC as a potential burden to employers and colleagues:

> And then, of course, there's the change in the attitude of the other workers there, and it's asking a lot, it really is. Explaining to the members of staff what is likely to happen when you've got someone with Asperger's in the office. (Donald)

Delay in diagnosis was reported by six of the ten participants who expressed frustration at lost opportunities for support, should a diagnosis have been made earlier in life. This was exacerbated by many, as they had been aware of their social difficulties for many years previously:

> Again another perplexed frustration I have is, why wasn't this spotted earlier? (Brian)

> Yeah. It would have been far better if I had known earlier. The thing is I didn't really know anything about it to be honest with you. I just thought I was shy, but it was a bit worse than that. (Frank)

> And for probably about twenty, thirty years now I've been saying that I've got some kind of social disability, which is a pretty decent description of Asperger's I suppose. But until I had got my diagnosis there was no help available, well no recognition of… and no help available. (Donald)

However, two participants did raise potential benefits to receiving a diagnosis later in life, in terms of promoting individuals' capability of coping on their own, without support and not using their diagnosis as an 'excuse':

> But then sometimes I also feel that if [my diagnosis] had come too early, there's a tendency with this sort of thing to over compensate. To sort of perhaps say it's not his fault he's got Asperger's, or to not sort of push yourself out into the world or whatever. (Elliott)

6.2. Barriers to transition

All ten participants highlighted barriers to their transition success. 'Socio-economics', 'Physical accessibility' and 'Autism spectrum condition' were highlighted as subthemes.

Socio-economics were considered barriers in transition to work by nine of the ten participants. This related to the influence of government policy on individuals with ASC and the support they receive. Participants expressed frustration at government policy and lack of employment opportunities in the context of the financial downturn in the UK:

> The main barrier with this, in which… well, the… well our present leaders at the moment is to get everybody off incapacity benefit and into work. And it would present a bit of hesi-… hesitation, frustration and confusion among the people with autism. (Samson)

> But at the moment it is quiet... it is quite difficult finding a job, because there's just not a lot of vacancies out there. (David)

The benefits trap was highlighted by seven participants as a significant socio-economic barrier to them being able to move towards full time employment. Although benefits were experienced to be a welcome support in preparation for employment, the system was experienced to be confusing and lacking in flexibility:

> So being on benefits at the moment is quite a life saver until I can find a job (David)

Another change I would have mentioned about the financial part would have been clearer rules on er… on er… on how these payments would have been affected if… for people who are on income support, on housing benefit, council tax benefit, disability living allowance, and incapacity benefit. (Samson)

Particular difficulties were experienced with regard to the 16 hour weekly work limit before benefits are withdrawn. This was felt to limit participants' ability to gradually increase their work hours and possibility of financial stability in transition to work:

I can only work up to sixteen hours. Because it affects me benefits. (Jade)

I could be seriously worse off than I am now, and that is one of the things about having a job, you've got to be financially better off and I need stability. (Donald)

Physical accessibility of support services was considered a salient barrier to transition for seven of the participants. They raised concerns over how public transport does not always link up with the location of services, how financial barriers impact their ability to travel independently and how they often have to rely on support for transport.

No I am not good on public transport. I have never liked being on buses. Even at a young age I didn't like buses... Dad brings me every day. I have got a driving licence but I can't afford the insurance. (Frank)

So for example if you were living in this sort of area, it is only a direct train from here to [place A]... so you would have to catch three or four trains to get to [place B]. (David)

Some participants also commented on how anxiety can be a factor in accessing services independently:

For instance, when they're travelling from one place to another that they are not familiar with… anxiety is one of the big main barriers. (Samson)

ASC characteristics were also experienced as a barrier to transition by all ten of the participants, related to both of the areas of difficulty highlighted by the DSM-V (APA, 2010):

> You've got to be flexible, have good communication skills, that's not me. (Donald)

Social and communication difficulties were identified as a highly important subtheme by eight. Participants highlighted the importance of social interaction at work, as well as the difficulties they experienced with communication attributed to ASC:

> But, in the end, having a job is not just about being able to do the job, it's about being able to fit in and that's where I'm lacking, and where people with Asperger's and Autism. (Donald)

> Barriers if you will. One being communication, one which is the biggest barrier, in which peop-… some people with autism and Asperger's tend to struggle with communication. Sometimes I do that, sometimes I struggle as well. (Samson)

> How autism really works is if you're feeling like something that's holding you back from you're trying to say. Like wrong words are coming out, for example, when you're trying to say the right words, and then it's mixing up the words for you. (Bruce)

A further consideration was that a preference for direct communication and honesty may offend others in the work place:

> Yeah, I prefer directional, a spade is a spade. Other people make a song or dance about it. (Andrew)

> And it's the blatant honesty. "Does my bum look big in this?" "Yes love, but it looks big in everything." (Donald)

Routine and rigidity issues were equally identified as adversely impacting upon transition. Participants stated a preference for routine and identified how a job may be a positive influence in providing this:

> It imposes some routine on me and having Asperger's I crave routine, that's probably one of the things that I think I'm lacking most from not having a job. (Donald)

However, they also stated how this preference may lead to difficulties with rigidity in work behaviours:

> That's it. I do like a routine. Just anything new I struggle to deal with that. (Frank)

> I don't like just walking out and leaving it, because it is a bit… So I have got an hour each day, but I usually only take half an hour for lunch and that's it. (Frank)

Participants described how cognitive features of ASC might impact their ability to focus on relevant work behaviour, but also highlighted ways in which they might be supported to work with these:

> It's not that I don't see things, it's that I see everything and get it… it's sort of the filtering out is the hardest part. Whereas other people will filter out a lot easier and focus on whatever it is they're supposed to be looking at, or for. And I'll find that diff-… I quite often find that difficult. (Elliott)

> You walk into a room and see that it's untidy or whatever, and a person with Asperger's walks in and sees a coffee stain in the shape of Africa, three pins on the sideboard, some dust on the television, whatever. (Elliott)

> Just like to break things down with you and like learn you a bit better. (Jane)

A further factor, associated with rigid and repetitive behaviours, is sensory processing differences (APA, 2010). These were reported by three participants in this study and highlighted as potential complicating factors in employment success, comfort and well-being for the individual:

> But some lights, the fluorescent strip lighting that's quite annoying, because you can see it, and you can see that... shifting, you can see it like cycling and strobing. And if it goes dim for a second you notice that. I look around and I'm like, oh, look at what's happened. And other people like don't even notice that the light is dimming and going bright, and sort of shimmering, and it hurts the eyes as well. (Andrew).

Despite all of the potential difficulties in successful transition to work for individuals with ASC, it was evident from the ten people interviewed that, with effective and well planned support, positive experiences of transition to work, employment and team working were likely.

6.3. Additional transition support considerations

Transition support is primarily discussed in the journal paper (see sections 3.4. and 3.5.). Further considerations are discussed here, which were beyond the remit of the journal paper.

One of the support groups discussed, attended by two of the participants, was a psycho-social group based on assessing strengths and barriers to work and actively working towards supporting individuals with mental health difficulties into work (Real Dawn, 2011). Whilst one of the participants found the mix of individuals with ASC and mental health difficulties to be detrimental, both found the content of the group useful in building work skills and gaining confidence. The groups have been shown to achieve about 25% employment rates following attendance and move a further 50% towards employment success (Real Dawn, 2011). The founder of Real Dawn believes that this skills focussed approach is particularly useful for individuals with ASC who have attended his groups (personal communication, 2011). Clavenna-Deane (2011) demonstrated the efficacy of a cognitive behavioural therapeutic group with a similar remit. The transition to work experiences of these group members are supportive that this type of group benefits the transition process and could be considered part of the either 'Encounter' or 'Adjustment' to transition (Nicholson, 1990), depending on whether they are intended to 'skill-up' an individual for a new or future work role, or to help them meet the demands of existing, established employment. Groups and training provided by statutory services were found not to be helpful in this sample. The majority of these were delivered by the Job Centre and focussed on support with CVs and job searching for a mixed group. These experiences suggest that groups to support individuals with ASC into work are most effective when they are ASC specific, focus on work skills, consider emotional aspects of transition and are delivered by specialist services with relevant expertise.

The general positive experiences of support expressed by the majority of the participants contrasts with the two participants in this study who were currently not being supported to transition to work and reported feelings associated with social isolation, best encapsulated by Donald:

And then it dawned on me how important it is for paid work; a job title, status and dignity, and it were cruel. It were torture. I've had thirty years of social isolation and I can't put that back right... The whole world revolves around it. I listen to the radio and it's rush hour, it's drive time, it's if you're coming home from work and it just cuts me up inside knowing that I'm not part of that.

This corresponds to a lack of 'Social integration' and highlights the importance of work for many individuals with ASC. The individual costs of failed transition are prominent in this context, but not supported by frequency or saliency in the analysis. This reaffirms the need for a better understanding of what constitutes effective transition support, which study attempts to provide through consideration of service user perspectives.

6.4. Theme maps and overview

Themes were mapped schematically, as suggested by Braun and Clarke (2006), and show theme saliency (Buetow, 2010) and frequency. Table 2 gives an overview and brief description of each theme and first-level sub-themes.

Figure 2. 'Diagnosis' theme map
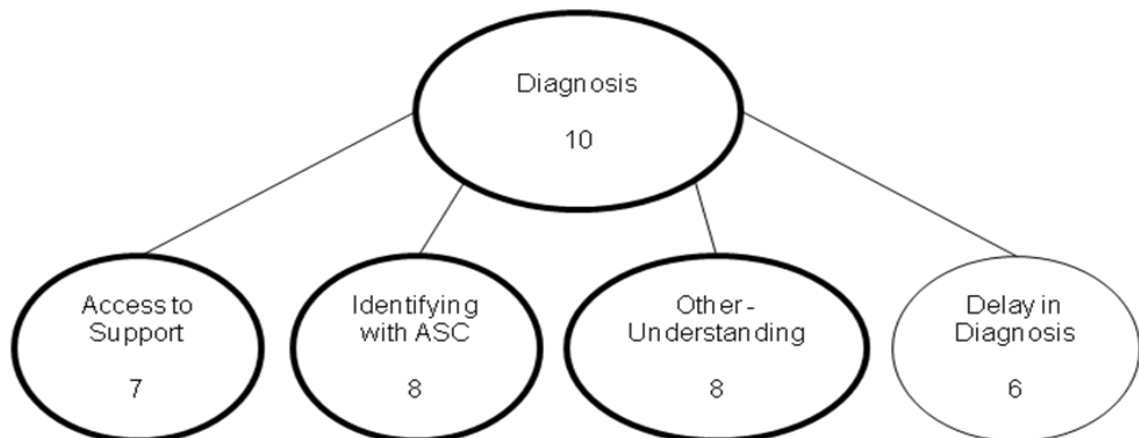
Bold circles: salient themes
Numbers: frequency

Fig 2.

Figure 3. 'Barriers to Transition' theme map

Bold circles: salient themes
Numbers: frequency

Fig 3.

Table 2. Themes overview

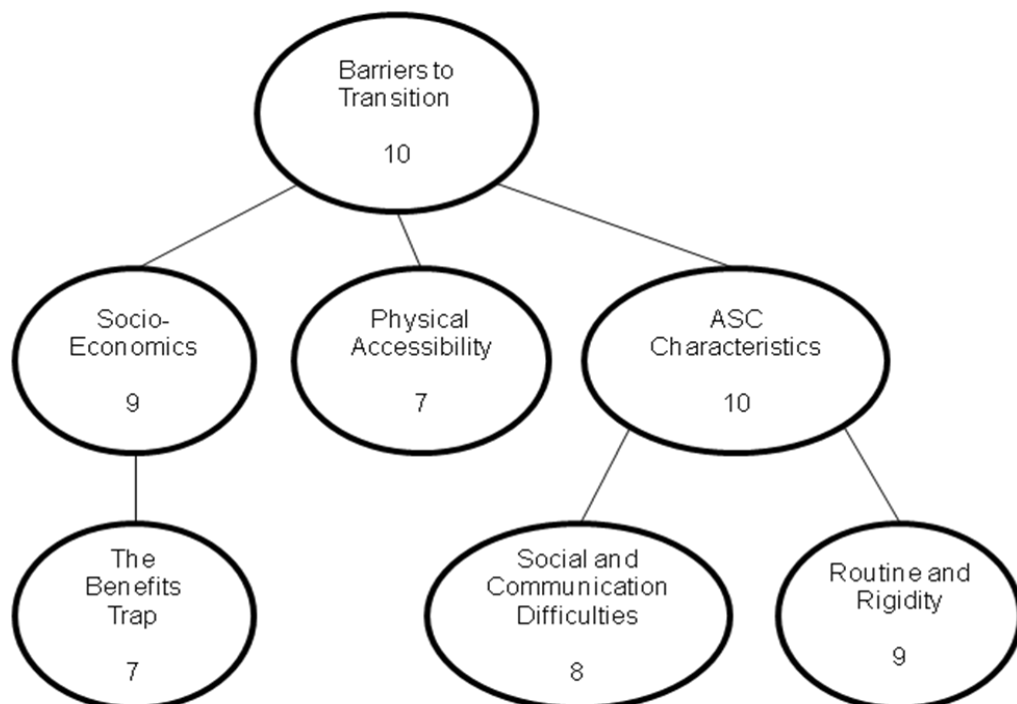| Theme	Sub-themes	Description	Typical quote	Frequency[1]	Saliency[2]
Diagnosis	Access to support	Diagnosis provides access to support	With my diagnosis of Asperger's syndrome everything changed, I was now eligible. I was able to get that extra support, so I have been out of the circle of being a statistic on the unemployment thing, to being pushed to the front of the queue. (Brian)	7	High
	Identifying with ASC	Diagnosis led to increased self-understanding and identification of strengths associated with ASC	And it's made me feel, in some ways, less concerned or less worried because it's answered a lot of questions. It's like I'm not just a freak, there's a reason for it, is the sort of feeling I got since my diagnosis. (Elliott)	8	High
	Other-understanding	Diagnosis led to recognition and acceptance from others. Negative perceptions exist and increased awareness of ASC is needed	And then, of course, there's the change in the attitude of the other workers there, and it's asking a lot, it really is. Explaining to the members of staff what is likely to happen when you've got someone with Asperger's in the office. (Donald)	8	High
	Delay in Diagnosis	Frustration due to late diagnosis, feeling that opportunities had been lost and awareness of difficulties long before	Yeah. It would have been far better if I had known earlier. The thing is I didn't really know anything about it to be honest with you. I just thought I was shy, but it was a bit worse than that. (Frank)	6	Low
Barriers to Transition	Socio-economics	Limited job opportunities and flexibility in transition to work due to government policy and benefit restrictions	But at the moment it is quiet, it is quite difficult finding a job, because there's just not a lot of vacancies out there. (David)	9	High
	Physical accessibility	Location of support is important and reliance on transport and anxiety when travelling are limiting factors	For instance, when they're travelling from one place to another that they are not familiar with… anxiety is one of the big main barriers. (Samson)	7	High
	ASC Characteristics	Social and communication difficulties, routine, rigidity and sensory processing differences as barriers	You've got to be flexible, have good communication skills, that's not me. (Donald)	10	High

Theme	Sub-themes	Description	Typical quote	Frequency[1]	Saliency[2]
Transition support	Emotional needs	Emotional difficulties experienced in relation to transition, as well as external factors. Training and support was limited.	It was because some people with autism and Asperger's tend… tend to find themselves really… Really frustrated in certain situations, in which erm… Apart from when they get the training, they learn to cope with it better. (Samson)	6	Low
	Clear guidance and honest feedback	Receiving advice and honest feedback from a variety of sources. Helping to identify strengths.	Not everyone with Asperger's is the same in terms of what they are good at and aren't good at, and what they find easy to deal with and what they don't. Yeah, and they were sort of, sort of profiling I suppose on what I was good at and what I was like. (Elliott)	10	High
	Practical support	Material support, aid and reliable alliance in transition preparation, encounter, adjustment and stabilisation	The most useful part was the work placement bit, which allowed me to be… get a bit more confidence in it, and er… and to… and the trying… to try and do the appropriate actions that an employee would do. (Samson)	10	High
	Social integration	Positive interactions with colleagues, acceptance and meeting others with ASC	And I felt that I wasn't alone, because at the time I felt I were the only forty-five year old bloke in [place D] who'd never had a job, which might well be the case. But at least now I'm not the only person who has got Asperger's who has never had a job. So there's a community. (Donald)	6	Low

[1] The number of participants who identified the theme.

[2] The subjective importance of the theme, assigned on the basis of the researcher's perceptions of how important, or salient, the theme was for the participants (Buetow, 2010).

Table 2.

7. Extended discussion

The research implications of the 'Transition support' theme are discussed in the journal paper (see section 3.5.). The implications of 'Diagnosis' and participant experiences of 'Barriers to transition' are discussed below.

7.1. Diagnosis

Diagnosis can have a massive influence on the experience of transition to work for individuals with ASC. Subjectively, this was perhaps the most salient theme identified by participants, despite a number of other themes being rated as similarly frequent and salient (Buetow, 2010).

Delay in diagnosis may lead to frustration, precipitated by lost opportunities for appropriate support and self understanding; strengthening the need for emotional support (Sherbourne & Stewart, 1991) in this context, as explicated in the journal paper (see section 3.5.). Common patterns of misdiagnoses and numerous referrals between inappropriate agencies highlight the need for increased informational support (Sherbourne & Stewart, 1991) at the service level, and in wider systems; congruent with the aims of the Autism Strategy (DoH, 2010a). Delays in diagnoses are characterised by a lack of support, when, in fact, individual need is greatest. There is an apparent need for increased investment in diagnostic services and more comprehensive service provision, so as to reduce the occurrences of individuals 'falling between gaps in services', as highlighted by the DoH (2010a). Late diagnosis and postponed access to appropriate support, potentially negatively impacts mental health (Barnard et al., 2001). DoH (2010a) and NICE (2012) documents suggest that this very issue is high on the government's agenda and hopefully this will filter down to the reality of service provision in the near future.

Receiving a diagnosis may be experienced by individuals as 'recognition' by society, and following this, a sense of social identity (Holland et al., 1998). An implication of this is that prior to diagnosis, some individuals feel unrecognised and neglected by society. This may be compounded by lacking a sense of belonging (Steward et al., 2009), fulfilment and self-esteem as a result of unemployment (Price, 2011). Although not constituting a theme in its own right, this phenomenon of 'societal

neglect' was experienced by individuals as contributing to low self-esteem, frustration and low mood. This may not have reached sufficient frequency or saliency due to the tendency of individuals with ASC to neglect emotional and relational aspects of their support (Downs & Smith, 2004), tending to focus on the tangible and informational.

A diagnostic label can be experienced as an explanation for perceived differences from others, supporting social identity development (Holland et al., 1998) and social 'in-groups' (Tajfel & Turner, 1986) through companionship with others with ASC (Punshon et al., 2009). Diagnosis therefore provides one of the most important sources of informational support (Sherbourne & Stewart, 1991) for individuals with ASC transitioning to work. It provides access to specialist services and self understanding that help to instigate the initial 'Preparation' stage of transition (Nicholson, 1990). Diagnosis also provides individuals with the opportunity to gain positive social interaction support (Sherbourne & Stewart, 1991) through new social groups with which they identify. This is likely to be beneficial to their sense of belonging and emotional well-being (Punshon et al., 2009). Diagnostic labels also provide access to tangible supports in the form of state benefits and service provision, which may alleviate financial constraints, boredom and social isolation (Price, 2011).

In a work context, diagnosis may lead to increased understanding and acceptance from employers and colleagues, aiding the development of social identity (Holland et al., 1998). However, diagnosis also creates the opportunity for stigma and 'out-group' prejudice (Tajfel & Turner, 1986), although this was only reported at a societal level by participants, and not in work contexts. This may be due to the supported nature of employment accessed by the majority of participants. Employers are likely selected by support agencies, generally through some level of job matching, and informational support (Sherbourne & Stewart, 1991) is provided to the employer (see journal paper, section 3.5.). Perhaps, in a non-supported context, 'out-group' prejudices (Tajfel & Turner, 1986) against individuals with ASC may be more prevalent.

In contrast to victimisation and persecution of individuals with ASC, which might be expected as an obvious 'out-group' (Tajfel & Turner, 1986) in a work environment

dominated by neuro-typical individuals, participants reported supportive companionship from 'positive social interactions' (Sherbourne & Stewart, 1991) with fellow colleagues. This was reported to positively influence participants' ability to progress through 'Adjustment' to the work role, towards stabilisation, due to the relationship building required in this phase (Nicholson, 1990).

Receiving a diagnosis raises the possibility that individuals may hide behind the label, become reliant on support and potentially blame 'Autism' for all their difficulties. Support is likely to be most beneficial to the individual if it promotes personal responsibility and self-determinism (Gagne & Deci, 2005) through appraisal and informational support (Sherbourne & Stewart, 1991) to identify individual strengths and learning needs, as highlighted in 'Clear guidance and honest feedback' (see journal paper, section 3.5.). This will also reduce the possibilities for individuals to over-identify with their diagnosis, or experience it as increasing helplessness.

Further to recognition experienced as a result of diagnosis, participants reported a hope that awareness of ASC would increase in society. The Autism Strategy (DoH, 2010a) sets out the government's plan for increasing awareness and service provision for individuals with ASC. If realised, this will likely reduce stigmatisation and increase opportunities, within a more accepting and well informed society as integration and awareness of other social 'out-groups' is thought to decrease persecutory and biased behaviour (Tajfel & Turner, 1986). This may also function to increase individuals' sense of 'belonging', leading to associated benefits in emotional well-being (Punshon et al., 2009). Whether appropriate support services will manage to secure funding during economic recession remains to be seen. Further research into, and promotion of, the potential economic benefits of supporting individuals with ASC into employment (NICE, 2012), in addition to the individual benefits, is required.

In a transition to work context, diagnosis is likely to benefit individuals' sense of social identity (Holland et al., 1998), belonging (Punshon et al., 2009), self-esteem and self-determinism (Gagne & Deci, 2005), as a result of increased access to services providing the potential for choice and options. Participants highlighted that appropriate support is necessary in order that individuals with ASC can maximise

their potential in transition to work, promote self-efficacy, emotional well-being and work performance (Bandura, 1997). This is likely to increase the chance of sustainable employment due to benefits for both the individual and employers.

7.2. Barriers to transition

The current UK socio-economic situation influences the availability of jobs, as well as the rigidity of the benefits system. The leap from 16 hours to full time employment, imposed by current UK policy, is likely to be too great for many individuals with ASC accessing support services to accomplish in one go. In order for supported transition to employment to be economically viable, for both the individual and tax payer, the possibility for a more graduated increase in working hours is necessary. Money may be an important intrinsic motivator (Gagne & Deci, 2005) for individuals transitioning to work and it is important to ensure that individuals will be better off through increasing their working hours in order to increase the probability of transition success.

Poor physical accessibility of services supporting transition to work for individuals with ASC does not lend itself easily to intervention. Support agencies were predominantly voluntary sector organisations that relied on funding or payments from social care services and local authorities. Hence, they experienced constant pressure to provide services within tight budgetary constraints, limiting their potential to afford expensive premises with accessible transport links. Two of the agencies were looking to relocate to city centre facilities in order to improve their accessibility to service users at the time of the study. Services expressed an awareness of the physical access difficulties faced by participants, but this information was gained from informal conversations with agency staff, rather than as part of the research methodology.

Tangible support strategies (Sherbourne & Stewart, 1991), such as financial support to enable individuals with ASC to partake in driving lessons and run a car, or access public transport freely, may reduce some of the barriers related to physical accessibility of services. However, this does not address the behavioural rigidity or sensory processing difficulties (APA, 2010) which may impact upon an individual's ability to drive, or the social communication difficulties (APA, 2010) that may prevent them from accessing public transport. Tangible familial support in accessing services can be a great help, despite the potential for increased dependence as a result of this and, in some cases, reduced self-efficacy and self-esteem (Bandura, 1997). This highlights the need for comprehensive support, based on 'Clear guidance and honest

feedback', or information and appraisal (Sherbourne & Stewart, 1991), of individuals' capabilities, across wider issues than work based skills, so as to support access to services and facilitate progression through the transition cycle (Nicholson, 1990). Information and appraisal (Sherbourne & Stewart, 1991) allows for targeted support and development of personal skills, with the potential to increase independence, self-determination (Gagne & Deci, 2005) and self-esteem associated with this (Bandura, 1997).

Both the socio-economic and physical accessibility factors appear to be largely out of the control of individuals with ASC, or even the agencies supporting them. However, where agencies might be able to support is in the provision of 'information and appraisal support' (Sherbourne & Stewart, 1991) around benefit entitlement, transport options and physical accessibility factors. 'Emotional support' (Sherbourne & Stewart, 1991) (see journal paper, section 3.5.) for associated anxiety and frustration is also likely to be beneficial, but notably absent in this context. Emotional needs are easily neglected due to the tendency for individuals with ASC to focus on tangible support factors, rather than the emotional (Downs & Smith, 2004).

During transition to work, difficulties in both the social and communication, and routine and rigidity domains of ASC (APA, 2010) are likely to be experienced. Individuals may lack confidence, social skills and perspective taking ability. They may have a rigid cognitive style, attention problems, experience difficulty filtering information and have aversive reactions to sensory stimuli (see extended paper, section 4.1.7.). Individual or group training may support with these difficulties, potentially providing any of the four functions of support (Sherbourne & Stewart, 1991). As well as the 'tangible' and 'information and appraisal' support, associated with assessing and 'skilling-up' individuals, groups may provide 'positive social interaction' (Sherbourne & Stewart, 1991) and a sense of 'belonging' (Punshon et al., 2009). This is most likely when participants are well-matched in terms of ability and ASC diagnosis, facilitating establishment of peer support (Weidle et al., 2006) and social identity (Holland et al., 1998). Groups are likely to be best received and most beneficial to group members when they are delivered by ASC specialist agencies,

rather than generic statutory services. This is in line with DoH (2010a) guidance that services should be highly skilled and informed on ASC.

The risk of offending others appears to relate both to a rigid and literal communication style, as well as deficits in perspective-taking ability (Baron-Cohen, 1995; Barnes-Holmes et al., 2004). Exposure to social situations may help to develop this skill in time and some evidence suggests specific training applying Relational Frame Theory (Hayes, Barnes-Holmes & Roche, 2001) to perspective-taking ability in children with ASC, may enable individuals to be 'skilled-up' in perspective-taking ability (Murphy, Barnes-Holmes & Barnes-Holmes, 2005). In the future, agencies supporting individuals with ASC into work, may wish to consider such interventions, on the basis of further empirical support.

Sensory processing differences, associated with rigid and repetitive behaviours in ASC (APA, 2010) were only reported to negatively impact on transition by three participants. However, this does highlight a potentially easy target for intervention in supported transition. The DoH (2010a) states that individuals with ASC should have access to services that promote non-aversive sensory environments. Although not explicitly stated by the participants, it would be useful if individual's sensory needs were assessed, as an 'information and appraisal support' (Sherbourne & Stewart, 1991). Advocates and job coaches, as recommended by NICE (2012), could then work into employing organisations and support agencies to manage sensory stimuli in the work environment. This may be as simple an inexpensive as changing from fluorescent strip-lighting to conventional light bulbs.

All possible interventions discussed above seek to offer equal opportunities in employment for individuals with ASC through support with environmental and individual factors. Support that is valued seeks to negotiate barriers and provide individuals with self-determined choice (Gagne & Deci, 2005), promoting self-esteem, self-efficacy and productivity at work, with associated emotional benefits (Bandura, 1997). Such support is linked with sustained employment and personal gains for this sample, including reductions in emotional distress (Cohen & Hoberman, 1983) and

social and communication difficulties associated with ASC (García-Villamisar & Hughes, 2007).

8. Summary, reflections and implications

8.1. Summary

The findings from this study highlight that the personal transition experiences of individuals with ASC provide a valuable source of information when considering the implementation of government legislation (DoH, 2010a) and guidance (NICE, 2012). Individual support needs vary throughout the whole transition process, but consideration of Sherbourne and Stewart's (1999) four functions of support and the four stages of Nicholson's (1990) transition cycle may help to identify areas for improvement when supporting individuals through transition to work, or designing appropriate support services.

The participants in this study described transition to work as an emotional process, congruent with the existing literature on transition (Kubler-Ross, 1970; Liddle, Carlson & McKenna, 2004). They reported emotional lows, associated with delays in diagnosis, the benefits trap and poor support, as well as emotional highs related to successful transition, personal achievement and perceived gains. Emotional reactions to transition to work have been largely neglected by research studies to date and there needs to be much more consideration of the individual in the transition process, both in terms of future research and the practicalities of planning individuals' transitions to work. By better supporting individuals with ASC through transition to work, negative experiences are more likely to be avoided, distress will be minimised (Cohen & Hoberman, 1983) and sustained employment is more likely.

Participants in supported employment tended not to report the concept of 'mal-employment', as described by Romoser (2000), unlike those not in supported employment who expressed frustration and low mood. This would suggest, for this sample at least, that supported employment agencies tend to provided appropriate support, based on appropriate skills evaluation and 'information and appraisal' (Sherbourne & Stewart, 1991) to identify appropriate work roles and facilitate transition 'Stabilisation' (Nicholson, 1990) for individuals with ASC, greatly improving self-esteem and well-being in the process (Bandura, 1997). Systemic interventions such as the Autism Strategy (DoH, 2010) and NICE (2012) guidance will hopefully

decrease the incidences of people not being able to access such beneficial services in the future, through improved diagnostic systems and wider service provision.

The unique contribution of this study is that it highlights, from the perspective of ten individuals with ASC, potential transition to work support needs and how these might be suitably provided so as to reduce distress and increase transition success in terms of employment stabilisation. Consideration of psychological theories of support and transition may help practitioners to identify where support is lacking, as well as maximise the beneficial effects of existing support.

8.2. Critical reflection

Thematic analysis was found to be an appropriate methodology to investigate participants' experiences of transition to work. Through consideration of the literature on qualitative methodologies, it was considered whether an Interpretive Phenomenological Analysis (IPA) would be more appropriate, as this is more traditionally associated with experiential investigation (Smith & Eatough, 2007). However, IPA is ideographic in nature and usually associated with a social constructivist epistemological position, and as such is more restricted in the extent to which findings might be considered to transfer to the wider population (Robson, 2002). In contrast, thematic analysis, congruent with a critical realist epistemological position, would consider that if common truths are identified within a certain group of individuals then these may transfer to a wider, similar population. This difference in epistemological stance was felt to be an advantage to thematic analysis in meeting the aims of this research. A further consideration was that, by using a more interpretative approach such as IPA, or even latent thematic analysis (Braun & Clarke, 2006), that the 'neuro-typical' biases of the researcher might detract from the stereo-typically literal communication of individuals with ASC (APA, 2010) which logically would be more amenable to a semantic thematic analytic approach. However, these assumptions, whilst perhaps correct in relation to the comparison of other methodologies, did not translate to a smooth and logical application of a semantic level, inductive thematic analysis, as discussed below.

This study set out to use a semantic and inductive thematic analysis to provide results that were driven by the data provided by the participants. In practice, the

researcher experienced tensions in the collection and analysis of the data that often pushed them towards a more deductive approach, despite their attempts to resist this. On reflection, these tensions likely derive from both researcher and participant factors that influenced this study, from data collection through to analysis and write up.

Due to the intention to remain data driven, the researcher did not feel it appropriate to disclose information about their understanding of, and relationship to, ASC at the outset, as this was not felt relevant. Following reflection on the limitations of this study, and the clear influence of the researcher and their understanding of the evidence base, it is now recognised that more active engagement with the influence of the researchers' understanding of ASC is required. The researcher had two years experience of supporting adults with ASC in the community (including on work placements), as well as experience of working with numerous individuals with ASC over six years in psychological and forensic services as an Assistant and Trainee Clinical Psychologist. The researcher felt that they had a reasonably good grasp of the evidence base and understanding of ASC. Whilst this potentially brings advantages, it also highlights how past clinical experience of individuals with ASC may have influenced the way in which the researcher approached this study.

Despite pre-existing understanding of ASC and issues that might affect transition to work for this population, the researcher remained keen that their understanding of ASC did not influence the analysis, as it was their intention to represent the views of this unheard and neglected population. However, the analysis was much more informed by the researcher's understanding of the interviews than was initially intended. This is not to mean that the researcher intentionally applied their pre-existing assumptions to influence the analysis, although to some extent this is inevitable. At times, the researcher was able to use their clinical experience of working with individuals with ASC to facilitate the interview process and navigate the social awkwardness of many individuals with ASC. At other times, their preconceived understanding may have influenced the analysis, from the assigning of codes, right through to the finalisation of themes, and their description.

Efforts to be data driven and not influence participant responses led to an occasionally clumsy interview style, particularly during the earlier interviews, and with less verbal interviewees. The researcher often had to check the inferred meaning of various statements with the participants. This often involved the researcher making a suggestion as to the participant's meaning, which inevitably raises concerns about whether the interviewer could potentially be leading participant responses. However, in this study, participants were quick to highlight statements contrary to their intended meaning and clarify their perspective. As might be expected from participants with ASC, they did not appear to mediate their responses to please the interviewer, or to fit with social or societal norms. Despite some initial apprehension and clumsiness in interviews, the researcher learned that they did not need to be tentative in their style and suggestions to participants. As a result of this, later interviews may have seemed more 'leading' to an observer. However, this was the result of the interviewer's experience and learning from previous interviews, that they would be challenged over misinterpretations and misunderstandings. On reflection, there may be some incidences where this interview style may have resulted in the researcher unwittingly having led participants' responses. However, this is believed to be minimal, in contrast to the benefits of it in facilitating the interview process with an inherently difficult sample to interview, given their social and communication difficulties.

The researcher's concerns regarding placing a neuro-typical interpretation onto ASC information, as well as their understanding and past experiences, led to a constant tension between what was 'true', given the semantic participant reports and researcher understanding of how, why, and in what context, participants reported what they did. On reflection, the researcher acknowledges they tended to assume that if participants were talking about difficulties in their transition to work, this was related to their ASC, and thus coded their transcripts accordingly. Whilst the researcher feels this assumption was likely accurate in most cases, it demonstrates a potential area for researcher bias and deviation away from truly data driven, semantic and inductive analysis of an ASC account. Examples of this tension are illustrated in appendix 8. For example, the researcher used the term 'social support' in coding participant transcripts, when participants had not actually used this terminology. Also, when Frank discussed his confidence and social difficulties in the interview process,

the researcher assumed this was related to his ASC diagnosis, as the context of the interview suggested. However, this was not explicitly stated by Frank (see appendix 8). A further area where the influence of researcher bias may impact this study is in the considerarion of saliency. Similarly, this process was undoubtably more influenced by the contextual factors of the interview and the researcher than originally intended.

During analysis, the researcher was aware of the implicit additional information that each code carried with it as a result of their involvement with the interview process, which was not necessarily represented in its entirety by the code title. This was discussed in research supervision, and from this developed a confidence that the researcher's perspective on the codes presented was valid, given their involvement. On reflection, this may also have opened up a certain amount of freedom, in terms of the researcher's willingness and readiness to interpret participant data that was surplus to that semantically represented by the codes. In many respects the process of analysis was experienced by the researcher as a framework around which they structured their own experience and understanding of the collective interview processes, largely, but not exclusively, reliant on the semantic labels of the coded data.

The difficulties and opportunities for bias described above were observed to have potentially impacted the analysis, not only in coding, but also in the way specific themes where structured and labelled. Analysis identified 'Social and communication difficulties' and 'Routine and rigidity' as sub-themes within 'ASC characteristics'. Given that these represent the two factor model of ASC (APA, 2010), care was taken to ensure that these themes were data driven and inductive, rather than deductive and informed by the evidence base (Braun & Clarke, 2006). Peer review of themes by the second author, keeping a reflective log and checking the quotes used to describe the themes with the corresponding participants, helped to minimise deductive bias. The naming of these thematic categories was undoubtedly influenced by the researchers' knowledge of the evidence base. However, the data fits well with this categorisation and Liddle et al. (2004) suggest that thematic similarity to existing theory can reinforce the findings of a study, viewing it as a strength, rather than a

methodological difficulty. Similarly, the subthemes within 'Practical support' closely represented the transition stages in Nicolson's (1990) model. This was felt to support the validity of the model but also highlight its relevance to an ASC population in transition to work.

An example of researcher influence on the analysis is the naming of the theme 'routine and rigidity'. Whilst numerous participants use the terminology of 'routine' and refer to how they do not like change, only one explicitly refers to 'rigidity'. During coding and analysis of the data, the researcher has paraphrased participant comments, perhaps in the context of their understanding of the prevalent model of ASC (APA, 2010), resulting in the naming of the theme as such. Despite this, the researcher feels that they represented the concepts conveyed by participants during the interviews appropriately and the naming of the theme is concordant with this. However, the analysis arguably would have benefitted from adhering more closely to participant language so as to promote an ASC perspective of transition to work, using ASC language and adhering to the semantic and inductive aims of the study. A counter perspective may be that applying theory-concordant language to the concepts participants represent helps professionals in the field access and apply the findings of this study more readily.

The theme names have undoubtedly been influenced by researcher factors, their theoretical perspective, clinical, research and personal experiences. However, it is felt that the concepts represented by the themes remain true to the participant accounts. This phenomenon is not uncommon in qualitative research and serves to add weight to the validity of the respective theoretical models (Liddle et al., 2004).

This was the researcher's first experience of using a qualitative methodology and of using thematic analysis. This led to feelings of anxiety, especially around how to manage and analyse the data. The researcher sought a research tutor with experience of conducting TA research and with clinical and research experience of individuals with ASC, in order to limit this anxiety and offer advice regarding the interview and analysis process. Whilst this was undoubtedly beneficial in reducing the researcher's anxiety, it is possible that the research tutor shared many of the

preconceptions and experiences as the researcher, and therefore may have unwittingly supported any researcher bias that influenced the analysis. On reflection, the analysis may have benefitted from peer review by someone less familiar with ASC, but with similar experience of thematic analysis methodology.

Given the complexities of applying thematic analysis methodology to an ASC population and the variability in participants in terms of social skills, cognitive ability and social communication ability, thematic analysis proved a useful framework for drawing together diverse experiences into a detailed and meaningful account. The researcher is not aware of thematic analysis being widely applied with individuals with ASC. Researchers applying thematic analysis to participants with ASC, or other groups with atypical social communication abilities, need to be aware of the issues discussed above and sufficiently account for these in their research design and analysis.

At the time this project was conceptualised and designed, some important studies cited had not yet been published (Brugha et al., 2011; NICE, 2012). This highlights the exciting and dynamic nature of this research field and the keen interest that exists in academic and clinical settings in finding and promoting ways of effectively supporting individuals with ASC into employment. The fact that the findings from this study compliment the NICE (2012) guidelines, in terms of supporting many of the suggested strategies, as well as adding a valuable insight into the experiences of service users, is encouraging. It is hoped that this rapidly growing and mutually complimentary research evidence base will be instrumental in shaping the delivery of ever more successful transition to work services for people with ASC.

Considering the recent legislative promotion of the rights of individuals with ASC through the Autism Act (2009) and the Autism Strategy (DoH, 2010a), the future of transition to work support is relatively bright for individuals with ASC. Whether the current economic austerity, commented on by some of the individuals in this study, impacts local authorities' and commissioning bodies' ability to see past the initial cost of service provision, to the projected long-term social and economic benefits of providing effective transition to work support (NICE, 2012) remains to be seen. Of

concern, is that similar guidance has existed for a number of decades, since Wehman et al. (1986) suggested how best to support adults with ASC into work in the USA. Although their study has likely informed much of the research since, the practicalities of what is suggested remains largely unchanged. It is critical that more recent evidence, including the views and experiences of individuals with ASC interviewed in this study, add strength to the existing evidence base in order to solidify the current guidelines for supporting individuals with ASC into work (NICE, 2012) and ensure more effective service delivery. In the context of supposedly person-centred and user-led services, it is imperative that future research informing such services consults individual perspectives.

Despite the limitations of this study discussed above, there is considered no right or wrong way to conduct thematic analysis, or coding (Braun & Clarke, 2006), and themes are often abstract and fuzzy constructs identified by researchers before, during and following analysis which are inseparable from researcher influence (Ryan & Bernard, 2000). The researcher takes some comfort from this viewpoint and feels they remained committed to the representation of participant data throughout and maintained a systematic approach. This is despite some difficulties, relating to the researcher's inexperience in qualitative methodology, their past experience and pre-conceptions, as well as the inherent social difficulties in the sample. Given this, the researcher feels they have represented the participants adequately and to the best of their ability,. Should the researcher conduct further thematic analysis studies, they would attempt to 'tighten up' their chosen epistemological and analytical positions to aid the analysis process. They would also engage more in the process of being open about their reflections and short-fallings throughout the write up, as this is central to the imperfect and fluid nature of qualitative research.

8.3. Strengths and limitations

The unique insight into the transition to work experiences of participants with ASC is this study's strength. No previous studies have been identified which provide such a rich and detailed account of participants' experiences of transition to work. The limitations of this study relating to the recruitment strategy are discussed in the journal paper (section 3.5.). A further limitation of this study is that the majority of

psychological research into models of support and transition has been carried out on neuro-typical individuals and may not be directly applicable to people with ASC. Therefore, many of the suggestions and links made within this study need to be interpreted with caution as this study has considered existing research relating to transition to work for individuals with ASC in the context of these models. Sherbourne and Stewart's (1991) model of support and Nicholson's (1990) cycle of transition are largely congruent with the evidence relating to what best supports individuals with ASC achieve successful transition to work. This highlights the utility of considering these models, applied to transition to work for individuals with ASC, as well as the need for more research into the application of psychological models to the field.

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Appendices

Appendix 1. Ethical approval

UNIVERSITY OF
LINCOLN

Lincoln, 8-7-2011

Dear Thomas Brockwell,

Thank you for your reply from 20-7-2011 to our letter from 8-7-2011. The Ethics Committee of the School of Psychology would like to inform you that your project on "Autism and Transition to Work" is:

☐ **approved**

☒ **approved subject to the following conditions:**

In your reply to point 3 you state that all logos relating to Autism Plus have been removed. This is not the case for a revised version of the participant information sheet, the consent form, etc. that you sent to us in your reply on 20-7. In fact, the logo now appears twice on every page. Could you check and remove the logo from all paperwork related to the research project?

That you provide confirmation from a source within the University (for example, as suggested in our letter the Secretariat and Legal Services or Human Resources) about whether the contract you intend to use for your data transcription is a document that is recognised by the University of Lincoln as a legal document before you use this contract, or that you use a different contract that is recognised by the University of Lincoln should this not be the case.

☐ **invited for resubmission, taking into account the following issues:**

☐ **is rejected. An appeal can be made to the Faculty Ethics Committee against this decision (cawalker@lincoln.ac.uk).**

☐ **is referred to the Faculty Ethics Committee. You will automatically be contacted by the chair of the Faculty Ethics Committee about further procedures.**

Good luck with your project..
Yours sincerely,

Emile van der Zee, PhD

Chair of the Ethics Committee of the School of Psychology
University of Lincoln, Department of Psychology
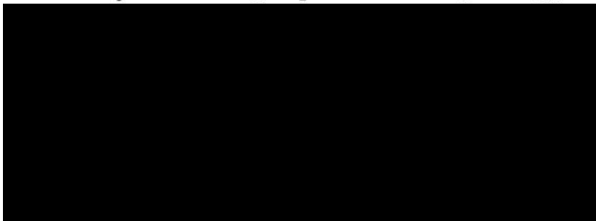
Copy of final Email confirmation:

Hi thomas, if the conditions are fulfilled you automatically have approval for the study - good luck with your study, all my best,

Emile

Sent from my iPad

On 25 Aug 2011, at 17:48, "Thomas M Brockwell ███████" < ██████████████████████ > wrote:

Hi Emile,

Todd Hogue forwarded me the ethics committee's feedback for my study, which was approved subject to conditions, on 5.8.11 (attached). The two conditions stated were that I correct the formatting to remove all Autism Plus logos and that I used a transcriber contract which was authorised by the University of Lincoln, rather than the one from the DClin Psy handbook. I replied to yourself and Todd on 11.8.11 having implemented these conditions and attached the new transcriber agreement (also attached) which was developed by Ann-Marie Noble in the Registrar's office at the University of Lincoln (contact details below). Todd replied saying that you needed to consider these amendments and would be in touch. I understand that you are on annual leave, so apologies for continuing to pester you on this, but I am eager to hear from you regarding whether I have met the conditions for approval or not.

I am keen to get this study underway as soon as possible as I have a four week study block starting on the 5th September which I need to utilise to its full potential in order to be able to meet the thesis deadline. If it is only the transcriber agreement which is a barrier to me commencing the study, would it be acceptable for me to start recruitment and data collection, pending approval of the transcriber agreement? This would also enable me to start transcribing some of the data myself if there were remaining difficulties with the transcriber agreement.

I have copied in members of the DClin Psy course team so that they understand my current predicament should I require a further extension (which is likely if I am not able to use the four week study block), and so that they may be able to offer me guidance on how to proceed in your absence.

Regards,

Tom

Tom Brockwell
Trainee Clinical Psychologist
Trent Doctorate in Clinical Psychology

Appendix 2. Participant information sheet

UNIVERSITY OF
LINCOLN

Participant Information Sheet

Title of Project: Autism and Transition to Work: A Thematic Analysis of
Service User Experiences (Version 2: 12.07.2011)

Name of Researchers: Mr Tom Brockwell – *Chief Investigator*
Dr Anna Tickle – *Research Supervisor*
Mr Craig Sutherland – *Field Supervisor*

We would like to invite you to take part in our research. Before you decide, we would like you to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully.

Part 1 tells you why this research is happening and what will happen to you if you take part. If you read Part 1 and are still interested in taking part, Part 2 gives you more detailed information about the study.

Talk to others about the research if you wish. One of our team will go through the information sheet with you and answer any questions you have before you agree to participate, this should take about 30 minutes. Please ask us if there is anything that is not clear or if you would like more information. Details on how to contact us are available at the end of this information sheet.

PART 1

1. Why is this research happening?
Current research suggests that people with autism often struggle to find jobs, especially when they have not been working before. Leaving education, like school or college, and moving into a work environment is called 'transition to work'. Work can either be paid or voluntary, as well as supported or unsupported.

Transition to work can be a very stressful time and people with autism may benefit from extra support to help them find a job and keep it. Lots of people have tried to come up with ideas about how best to help people with autism transition to work. Most of these people have been professionals who work with people with autism and not people with autism themselves. We want to find out from people with autism what it is like to 'transition to work'. We hope that by hearing the views and experiences of people with autism we can help to work out how to support people better in their transition to work.

We want to interview people with autism who have experienced a transition into a working environment. This does not need to have been recent but you do need to have a good memory of what it was like for you.

2. Why have I been invited?
You have been invited to take part because you currently access autism support services, have a diagnosis of autism, and have previously been through a transition to work.

Version 2: 12.07.11

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3. Do I have to take part?

No. It is up to you to decide whether to take part. We will describe the study and go through this information sheet with you. If you agree to take part, we will ask you to sign a consent form. You are free to stop taking part at any time, without giving a reason. This would not affect the standard of care or support you receive. Further details are provided in part 2.

4. What will happen to me if I take part?

If you decide to take part in this study you will be asked to read and sign a 'consent form' to show that you understand what is required of you and agree to participate. Even if you sign this form, you have the right to withdraw your consent up to a week after the interview. After you have signed the consent form an interview will be arranged at a convenient time and place. This interview is likely to last about an hour, but can be shorter if you think that would be too long. The interview will be about your experiences of your transition to work. The interview will be recorded on a digital audio recorder and later typed up word for word.

You will be interviewed once, but we are hoping to interview nine other people. All of the information from your interview and from other participants' interviews will then be compared. The aim will be to find out the most common and important issues affecting the people that were interviewed.

The research is planned to be completed by February 2012. Interviews with the researcher are not psychological therapy and no therapeutic work is intended to take place during the interviews. This study will not affect any of the routine care or support that you receive.

5. Expenses and payments

You will receive a £10 high street voucher for taking part in this research study and completing the interview. Interviews will take place at your place of work, your home or another location that is easy for you to get to without paying to travel.

6. What are the possible benefits of taking part?

There may not be any benefit of taking part in this research. The interview might help you to think and talk about your experiences of transition to work. Also, by taking part in the research you might help professionals understand what transition to work is like for someone with autism and how to provide better support. In the future, this may help others with autism find and keep jobs.

7. What are the possible disadvantages and risks of taking part?

It is not thought that this research will cause you harm. You will not be forced to talk about anything that you do not feel comfortable discussing. If the interview does make you feel uncomfortable, worried or upset then you are free to take a break or stop the interview at any time. At the end of the interview, after the recorder has been turned off, you will be able to speak to Tom, the Chief Investigator, and ask any questions.

8. What if there is a problem?

Any complaint about the way you have been dealt with during the research or any possible harm you might suffer will be addressed. Please see part 2 of this sheet for more information.

9. Will my taking part in the research be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The only time confidentiality would not be kept is if you disclosed any information relating to a risk of harm to yourself or others, or act of crime being committed. The details are included in Part 2.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

PART 2

1. What will happen if I don't want to carry on with the research?

You can withdraw from the research at any time prior to the interviews, during the interview process, or up to a week after the interviews. If you withdraw, we will remove all information from the study that relates to you and delete all recordings and documents.

2. What if there is a problem?

If you have a concern about any aspect of the research, please speak to the researchers who will do their best to answer your questions. If you wish to complain formally about any aspect of the research, you can do this by contacting the University of Lincoln Ethics Committee Chair, Emile van der Zee. The contact details are listed at the end of this information sheet.

3. Will my taking part in the research be kept confidential?

Interviews will be recorded on a digital audio recorder. The recording and the consent form will be stored in a locked bag when being carried to and from the interview, when in a car they will also be locked in the boot. They will be transferred onto a secure computer at the University of Lincoln, or onto an encrypted data stick, at the earliest opportunity. Any paper records will be stored in a locked filing cabinet in restricted-access area of the Clinical Psychology Department, meaning that they cannot be looked at by the general public. All records will be stored under a fake name, or pseudonym. Only the chief investigator (Trainee Clinical Psychologist) and their research supervisor (Clinical Psychologist) will have access to which notes correspond to your real name. The personal information collected, such as your age, will be used to provide information to the write up of the research only and will be locked away in a separate filing cabinet.

If the interview takes place at your home, the researcher will need to make sure one of the other researchers knows where they are. The researcher will be required to let them know the location of the interview but not your name. The researcher will ring them when they leave your home to let them know they have finished the interview.

The only time confidentiality would not be kept is if you disclosed any information relating to a risk of harm to yourself or others, or act of crime being committed. In this situation, local service provider policies would be followed and safeguarding services informed. It is possible that the police would be involved if the researcher had any concerns about a crime being committed. Any information that is collected about you will be stored for seven years, after which time it will be destroyed.

4. Will any other health care professional be involved?

It is not necessary to seek consent from any other health care professional. However, feel free to discuss your participation with anyone who might give you independent advice.

5. What will happen to the results of the research study?

After all of the interviews are finished, they will by typed up, word for word, by the Chief Investigator, Tom Brockwell, or by a paid professional transcription service. If someone is paid to type up the interview they will not know any information about you, other than what is talked about during the interview. They will sign a confidentiality agreement that means they are not allowed to talk about the interview with anyone else. Any information that could identify you, or anybody else, will be removed or changed in the typed up version and you will be assigned a fake name which will stop people knowing your true identity. Only the Chief Investigator and Research Supervisor will have access to your real name. We will then spend some time analysing the typed up information from all of the different participants. We will try to find common 'themes' in the information and work out what are the most important issues raised for the participants in this study.

When the study is written up, direct quotes will be used from the interviews as examples. This means that something you say in the interview might be included in the research report. If we do wish to include something that you said in interview, you will be contacted and offered the opportunity to check that we are representing your views accurately. We will not include your name or any information that would let anybody else know it was you.

The results will be written up as a thesis which will form part of the Chief Investigator's requirements for qualification as a Clinical Psychologist. The study will also be written up as a journal article which will be submitted for publication in an academic journal and may be presented at conferences. Your identity will remain protected in all publications of this research study. If you are interested in the results, we will send you a summary report or the whole report if you would like one. Should you wish to be informed about the results of the research, please fill in the request form at the end of this information sheet.

6. Who is organising and funding the research?

The research is organised and funded by the University of Lincoln.

7. Who has reviewed this research?

In order to protect your safety, rights, well-being and dignity, all potential research needs to be checked by an independent group of people, called a Research Ethics Committee. This research has been reviewed and given favourable opinion by the University of Lincoln Research Ethics Committee. It has also been reviewed by a research tutor at the University of Nottingham.

8. Further information and contact details

Should you want further information, please refer to the following:

1. General information about research ethics: National Research Ethics Service: www.nres.npsa.nhs.uk

2. Specific information on this research project: Mr Tom Brockwell (Trainee Clinical Psychologist) or Dr Anna Tickle (Clinical Psychologist) using the details below.

3. Advice as to whether you should participate: Friends, family and professionals.

4. Who you should approach if you are unhappy with the research: Emile van der Zee PhD University of Lincoln Ethics Committee Chair
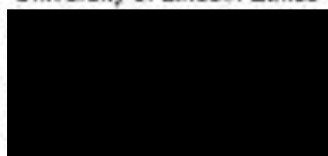
Chief Investigator
Tom Brockwell
University of Lincoln

Researcher Supervisor
Dr Anna Tickle
University of Nottingham

Appendix 3. Expression of interest form

EXPRESSION OF INTEREST FORM

Autism and Transition to Work: A Thematic Analysis of Service User Experiences

I _____ (NAME)

would like to discuss the study further with Tom Brockwell.

My preferred method of contact is:

Please tick box and provide details

Telephone _____ ☐

Email _____ ☐

Post _____

_____ ☐

My preferred day or time to be contacted is _____

Please send this form back to Tom Brockwell, using the SAE envelope or give it back to your support coordinator. Alternatively if you prefer to contact me please feel free to call me on ████████, or email me on ██████████████ and I will get back to you as soon as possible.

Many Thanks,

Tom Brockwell (Chief Investigator)

Version 2: 12.07.11

Appendix 4. Participant consent form

UNIVERSITY OF
LINCOLN

Participant Consent Form

Title of Project: **Autism and Transition to Work: A Thematic Analysis of Service User Experiences (Version 2: 12.07.2011)**

Name of Researchers: Mr Tom Brockwell – *Chief Investigator*
Dr Anna Tickle – *Research Supervisor*
Mr Craig Sutherland – *Field Supervisor*

Please initial box

1. I confirm that I have read and understood the information sheet dated 12.07.2011 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that taking part is voluntary and that I am free to stop taking part up to a week after the interview. I can stop without giving any reason and without my care or legal rights being affected. I understand that any information I have given will be removed and physical copies destroyed if I stop taking part. ☐

3. I understand that if I say anything which suggests that I or someone else may be at risk or that any crime has been committed, Tom will contact local safeguarding services and tell them what I have said. I understand that the police could get involved if I say anything about a crime being committed ☐

4. I understand that my participation and all personal information about me will be anonymised, which means my name will not be written in the report. ☐

5. I consent to the digital audio recording of the interview and anonymised quotations being used in the write up of the study. I understand that I will be given the opportunity to check any quotes used represent my views accurately. ☐

6. I consent to the digital audio recording of my interview being typed up by a professional transcription service bound by a confidentiality agreement. This means they would not tell anybody about what I have said in interview. ☐

7. I agree to take part in the above study. ☐

_____   _____   _____
Name of participant   Date   Signature

_____   _____   _____
Name of person taking consent   Date   Signature

When completed: 1 copy for participant; 1 copy for researcher site file; 1 copy for support agency file.

Version 2: 12.07.11

Appendix 5. Report request form

Autism and Transition to Work: A Thematic Analysis of Service User Experiences

REPORT REQUEST FORM

Please tick box

I would like to request a copy of the summary report for the above study. ☐

I would like to request a copy of the full report for the above study. ☐

Please could you forward me a copy using the contact details below:

Please select one option (tick box):

☐ By post to: _____

_____

_____

_____

_____

_____Post Code:_____

☐ Pdf file by email to: _____

Thank you.

_____   _____   _____
Name   Date   Signature

Version 2: 12.07.11

Appendix 6. Transcriber confidentiality agreement

Data Protection Act 1998 Confidentiality Agreement for Transcribers

This Agreement is made as of _22.9.11_ (Date), by and between the University of Lincoln, with principal offices at Brayford Pool Lincoln LN6 7TS (the University) and _SUE BARNARD_ with principal offices at _ACADEMIC TRANSCRIPTIONS, 52 BARTON ROAD, HASLINGFIELD_, (the Transcriber). _CB23 1LL_

The Transcriber has been appointed by the University of Lincoln to transcribe audiotapes/audio files and documentation resulting from research undertaken by _TOM BROCKWELL_ which will involve the disclosure to the Transcriber of personal data held by the University. Accordingly the Transcriber is required to deal with any such information in accordance with the terms of this Agreement and the Data Protection Act 1998.

The Transcriber undertakes to respect and preserve the confidentiality of personal data. Accordingly, for an indefinite period after the date of this Agreement the Contractor shall:

- maintain the personal data in strict confidence and shall not disclose any of the personal data to any third party;
- restrict access to employees, agents or sub-contractors who need such access for the purposes of the contract (and then only if the employee, agent or subcontractor is bound by conditions of confidentiality no less strict than those set out in this agreement, which the Transcriber shall enforce at the University's request);
- ensure that its employees, agents or sub-contractors are aware of and comply with the Data Protection Act 1998; and
- not authorise any sub-contractor to have access to the personal data without obtaining the University's prior written consent to the appointment of such sub-contractor and entering into a written agreement with the subcontractor including conditions of confidentiality no less strict than those set out in this agreement, which the Transcriber shall enforce at the University's request.

The Transcriber agrees to indemnify and keep indemnified and defend at its own expense the University against all costs, claims, damages or expenses incurred by the University or for which the University may become liable due to any failure by the Transcriber, its employees, agents or sub-contractors to comply with any of its obligations under this Agreement.

For the avoidance of doubt, the confidentiality imposed on the Transcriber by this Agreement shall continue in full force and effect after the expiry or termination of any contract to supply services.

The restrictions contained in this Agreement shall cease to apply to any information which may come into the public domain otherwise than through unauthorised disclosure by the Transcriber.

This Agreement shall be governed by and construed in accordance with the laws of England and the parties hereby submit to the exclusive jurisdiction of the English courts.

Signed for and on behalf of __ACADEMIC TRANSCRIPTIONS.__

Signed: _SABarnard_   Name: _S. A. BARNARD_

Title: _Mrs_   Date: _23 September 2011_

Signed for and on behalf of the University of Lincoln

Signed: _____   Name: _J M Presswell_

Title: _Programme Co-Director_   Date: _31 08 11_

Version 1, August 2011

Appendix 7. Interview schedule

Participant Information

Participant Pseudonym:

Gender:

Age:

Ethnicity:

Living Arrangements:

Employment Details, including when they made the transition:

Education Details:

Interview Introduction

Thank you for taking the time to speak to me today.

This interview will last approximately an hour, although it can be longer or shorter if you wish. The interview will be recorded on a dictaphone. Is that OK?

You can stop the interview whenever you wish and you are welcome to take a break if you need to.

Your name and identifiable information will be changed so that you are not identifiable. The only time I would need to break confidentiality is if you inform me that you or someone else are at risk of harm or if you tell me about criminal activity. Do you understand?

The purpose of this interview is to develop a really good understanding of your experience of moving into employment. There are no right or wrong answers – I am interested in hearing about your experiences in the way that you want to tell me about them.

Interview Questions

- Please tell me about your experience of your transition to work.

- What, if anything, was good about the transition to work?

- What, if any, support did you get during the transition?

- Was there anything that made the transition difficult? If so, what?

- What would you have changed about the transition if you could?

- What, if anything, did you learn about yourself during your transition to work?

Prompt Questions

- Was there anything you found helpful during the transition?

- Was there anything else that would have helped? If so, what?

- What, if anything, was bad about the transition to work?

- What, if anything, were the problems with the transition?

- Were there any people who were particularly helpful during your transition to work?

Debrief

- Is there anything else you would like to say?

- Thank you for taking part today.

- How did you find the interview?

- Do you have any questions?

Appendix 8. Coding excerpts

I: Interviewer: Tom Brockwell

R: Respondents A to J

A. Donald	
I There we are, okay. So, first of all then, if generally you could tell me sort of about your experience of transition to work, trying to find work?	
R Well, as I've mentioned before you switched the recorder on, I'm fifty next year, I've never had paid work. Nearly twenty years ago now I did twelve years pretty much full-time voluntary work. I was diagnosed two years ago with Asperger's syndrome, I've probably got Dyspraxia as well, but I'm not diagnosed with it and you can't get a diagnosis on the NHS apparently; and there's probably no advantage to getting a diagnosis. I've always known since being, I don't know, twelve or thirteen that I was a bit different, mainly by people's attitude. I got bullied a lot at school about me being quite big, as you can see; it wasn't physical, it was just mental. And for probably about twenty, thirty years now I've been saying that I've got some kind of social disability, which is a pretty decent description of Asperger's I suppose. But until I had got my diagnosis there was no help available, well no recognition of… and no help available. There's probably still not any help available, to be honest, but at least there is recognition, so that's an improvement. And, of course, financially I'm a lot better off, which means I can eat healthily and put my heating on in the winter.	50 Years old Never had paid work 20 years since last worked 12 years full time voluntary work AS Diagnosis Dyspraxia not diagnosed Can't get diagnosis on NHS No advantage to Dyspraxia diagnosis Known I was different since 12 or 13 Peoples attitude Got bullied at school Saying has social disability for 20/30 years Aspergers as social disability No help or recognition until diagnosis No help since diagnosis, but recognition Improvement since diagnosis Financially better off I can eat healthily Can afford heating in winter

I	And that's since your diagnosis?	
R	Since my diagnosis; and I've got my bus pass, so I can go walking regularly in the Peak District which is what I use as a job substitution I suppose. It imposes some routine on me and having Asperger's I crave routine, that's probably one of the things that I think I'm lacking most from not having a job. 'Cos I don't have any problems getting up in the morning and there's just nowhere to go. So it's either at the shops first thing for nine o'clock, or it's out walking in the Peak District.	Got my bus pass Can go walking Walking as job description Imposes routine on me Crave routine No job means lack of routine No problems getting up in the morning Nothing to do Shops as activity Walking as activity
I	Yeah. You mentioned that you did, was it voluntary work, supported work, was that?	
R	Erm not supported... I was a volunteer. I lived out in the [████], quite a unique area between [place █] and [place █], a coal-mining area; and when I say coal-mining there was nothing but coal-mining. [?02:44] and the entire economy collapsed and society collapsed and there was some money thrown in the direction of the area, you know, City Challenge bids and whatnot. And so there was some opportunities to get involved with volunteering. I did it. I enjoyed it. I think I was treated as pretty much as an equal by people I came across. But in the end it wasn't paid work. I chose what I wanted to do and what I didn't want to do, which you can't do with paid work. And... But in the end, well I moved to [place █], but the thing that really… Well I lost enthusiasm for it, were two things. The funding regime changed so that the place where I was based wasn't what it was, and what I wanted it to remain. You've always got to chase the funding. And it were the fact that, because I'd not got paid work I had got no status and no job title, and this was before	Lived in unique coal mining area Local economy collapsed and attracted money Volunteering opportunities Enjoyed volunteering Treated as an equal Not paid work Chose what I wanted to do Don't have choice in paid work Lost enthusiasm for volunteering Funding changed volunteering service Didn't want change Got to chase funding No paid work means no status

	mobile phones came in. And I had been in meetings with senior council officers, like the deputy head of planning, and they specifically said to me, well, the next day phone me up with details of this project. So I did do. I got through to the receptionist and she wanted to know what department I worked from. What company I worked for? And when I said well I'm just a volunteer, she wouldn't let me speak to him, even though he had specifically told me he needed that information. So I had to go to the office down the corridor where there's a paid worker who had got the job title, and she got through straightaway. And then it dawned on me how important it is for paid work, a job title, status and dignity, and it were cruel. It were torture.	Meetings with senior council officers Phoned with details of a project Wanted to know department/ company I worked for Just a volunteer. No access as volunteer. Contradictions in organisations Had to go long route Job title gives you access Importance of job title Job title means status and dignity Cruelty and torture.
I	And what sort of period of your life was… are we at now?	
R	Well this were nearly twenty years ago.	
I	Twenty years ago.	
R	Yeah, it were from the, well, where would it be? Mid-eighties to mid-nineties, so not quite twenty years ago.	
I	Okay.	
R	And at that time obviously, I didn't have my diagnosis because so many people were unemployed, I just probably got lost in the crowd which may be benefited the… They didn't see me as that different, there were that many people unemployed.	No diagnosis Many people unemployed Lost in the crowd Not seen as different as many people unemployed

B. Brian	
I	Do you receive support whilst you are at work? Or is it an autonomous role?	
R	It is hit and miss. I did receive support at the beginning but it seems to have dropped back a bit. I must be doing well that they don't need to keep seeing me all the time.	Variable support Reducing support with time Doing well = reduction in support
I	Okay.	
R	But yeah… But if I do have say emotional issues then I do have someone assigned to, who I go and speak to. If I have technical issues and then go and talk to my boss who will help me out that way.	Emotional issues Emotional support Practical support
I	Does that package of support work for you?	
R	Yes it does.	Support works
I	Would you change it in any way, if you could… if you could design it to be exactly what you needed?	
R	I have been having difficulties trying to access courses to make myself better, different packages. If you go to funding bodies on websites through direct.gov or whatever, there's funding there but it is for long term degrees kind of thing, over a couple of years. The courses what are available to me, to help me, are only two days long, so it doesn't qualify in the same way it would for someone else.	Difficulty accessing courses Desire to improve Limited funding for short courses Want short courses Want choice of courses
I	Yes. Okay.	
R	That's one of the difficulties I've had.	Difficulties

I	And in terms of finding the permitted work scheme here, how did you go about that and what support did you have in finding that?	
R	My last… Go into a bit of history here.	
I	Yeah. Sure.	
R	My last job was bar work and I was… at the end of 2003. As usual with the Job Centre you are in a cycle where you are unemployed for six months, then they put you onto a training scheme for six months. You complete that, and you are back employed for six months. It just kept going and going.	Long time since previous employment Job centre 6 month cycle of training/employment
I	Yeah.	
R	Thankfully, that's when my diagnosis came in. I did an interview previously where… I got diagnosed with depression first, anxiety and hyperactivity.	Thankful for diagnosis Misdiagnosis Anxiety Depression Hyperactivity
I	Okay.	
R	I went for… to speak to someone about employment and support allowance, and I had to go for a medical. I did the medical but they didn't allow me it because it wasn't deemed appropriate enough for the three things I had been diagnosed with to get extra help. With my diagnosis of Aspergers syndrome everything changed, I was now eligible. I was able to get that extra support, so I have been out of the circle of being a statistic on the unemployment thing, to being pushed to the front of the queue.	Resources Employment and support allowance Process/requirement Misdiagnosis impact Need for extra help Impact of diagnosis Eligibility Different diagnoses → different levels of support Change following AS diagnosis Recognition Out of cycle Front of queue

C. Samson

R	And I used to do stuff like erm… I'm just trying to think. I was using advanced computer software, for example, erm… Adobe… Adobe Photoshop, CS4, erm… which is to do some graphical work, and the other one which is Adobe [?After Effects], I think that's the name of it, [?01.26 pastel illusions], and other advanced software you may… may or may not have heard of.	Use of advanced computer software Lists programmes at which competent Advanced software
I	Okay, no well…/	
R	/Which was designed to do some graphical work. And er… and some task anima-… some 3D animation stuff as well, there's the 3D studio [?01.39 Mass], which is one of the… 3D computer software, I used to do a placement before that, that was… but that was… that was like several months ago.	Graphical computer work 3D animation work Skilled use of software Previous placement at employing support agency
I	Okay. And that was also at [ASD support agency], did you say?	
R	Yes, it was.	
I	Okay. And what sort of support do you receive whilst you're on those placements?	
R	The support I receive was like one to one support with er… with a lady from [ASD support agency].	One to one support from ASD employment support agency
I	Okay.	
R	And there was… and I had to fill in some forms with them, and er… The support is alright. And there was… and I was getting there with the… trying to get used to the world of work,	Had to fill in forms Support is alright Trying to get used to the world of work

	and the… and the support has helped me. Since I used to attend a programme where I was… I was [?02.20 helped] by [other ASD support agency] before which helps people into work, along with… along with two other service users [?2.27] time back in [?02.28].	Support has helped me Attended ASD employment programme Agency helps people into work Employment programme for group of 3
I	Okay.	
R	It was a programme that was designed for people in… who was in [ASD support agency], that… to do a… to… how you feel about the world of work, basically, and it was for example… sorry, I'll rephrase that, it was, for example, to erm… if the… the positive social model, the negative medical model, as it turns out [?02.50].	Programme designed for ASD employment to explore feelings about world of work Positive social model in group Negative medical model in group
I	Yeah.	
R	As well as examples in those, and… Is there like rights for disabled people as well as the general stuff in the world of work, and er… and what to do and what not to do.	Group – rights for disabled people Group - general stuff in world of work Group – what to do and not to do at work
I	Okay. And what was particularly useful for you, do you think, about that programme?	
R	It was really useful to help me gain the confidence in… in erm… in work. It helped me gain the confidence in trying to… so-… in working with… working with other… with other employees, and an employer, in erm… Sorry, I'm a bit nervous.	Programme helped confidence in work Helped in confidence with employees and employer Nervous in interview

D. David

I	Yes. The social worker again. What sort of support would you like which you haven't got?	
R	That I am not too sure, because I've already got support whenever I need it. You know I have got it most of the day, so I am not entirely sure. I am not even sure if I would need that support or not, but I think for example, if I was working in the pub, and I was working behind the bar, a member of my staff might sit in the car having a drink or reading the paper. I would just [?sat in there, if I need them], but when I've confident I will do this on my own. I feel I could do it.	Got whatever support needed Got support most of day Not sure how to improve support Not sure if need support Would like support staff close by, if needed Confidence would grow with time Confidence leads to decreased need Feel could work independently
I	And what do you think are the sort of situations where you might need them there?	
R	It is difficult to answer that unless I get that experience do you know what I mean? It is just difficult to know if I need it or not.	Difficult to predict situations support needed Difficult to know whether support needed
I	In terms of finding or getting another job can you think what other help you might you want to help you actually get the jobs?	
R	It would be helpful if some of the staff could give me a reference, or if the staff said to me we will let you do a couple of hours a week working for [ASD Support agency], for example cutting the grass, doing a bit of paper work, getting a couple of quid in my pocket a week, so I get used to the feeling, of what it feels like to get paid and to be professional. To get into that environment and that... to get into that system of getting a job. Since I got a job at [█] it was really nice, it got me into the system of getting into that. Because when I first came into [place █], when I first came to [place █] I wasn't that really interested. I wasn't looking	Helpful if staff could give reference Opportunity for few hours work a week Work opportunity in supporting agency Any opportunity / tasks Get paid Get used to feeling of being paid Get used to feeling professional Get into work environment / system Work experience got into work environment

	for a job. But since I've got into work it has given me a real big injection of getting that final... where I want to get a job.	Not looking for job initially Work experience given motivation to get job
I	Other than there being a shortage of jobs at the moment, as we know, what are the main barriers do you think to you getting work or a job. References you have mentioned. Is there anything else?	
R	Not that I know of.	
I	I am just going to... *[looking at questions]* What would you say, if anything, have you learnt about yourself during this sort of transition to work and working?	
R	I am not sure. I don't understand.	
I	In terms of what do you think... Is there anything you have learnt, skills that you have developed that will help you get more jobs in the future, do you think, from the work that you've done to date?	
R	Experience, patience, being polite erm... and just being a bit more wise to what sort of jobs you are doing and just getting in the... Just getting the more practice of working like. Getting that bit more experience having to deal with situations. So the more experience the better you know what you are doing.	Got experience Developed patience Developed politeness Wise to world of work Practice of working / Experience Got experience of dealing with different situations More experience leads to better knowledge
I	Yes.	
R	Because obviously the more experience you've got the more ideas you've got to help yourself. The more... You become more familiar with what you are doing. You know more on what you are doing.	More experience lead to more knowledge More knowledge leads more independence Familiarity improves work practice

E. Elliott

R	I think employers need to focus on the strengths and I think the idea of being more concerned with the level of accuracy of things. And things being done right and then fully, rather than being done to a certain target level is probably quite a common thing. I don't know, but that's the feeling I get and so... In terms of giving people target levels to achieve and hit, and aim for, they need to be able to be more flexible, even possibly more realistic might be a way of putting it. Because like a lot of jobs are sort of target level, you've got to do this, this, this and that in that amount of time.	Employers need to focus on strengths Employers could focus on accuracy Employer support for things being done fully and right, rather than targets Need to be more flexible or realistic about targets Lots of jobs are target driven Lots of jobs set time limits
I	Yeah. And in terms of, I suppose that links back into the pressure to meet those targets. Do you… have you experienced any other barriers to work other than that sort of need for pressure, any other sort of difficulties?	
R	I think possibly the social side of things and sort of putting myself across from the start from interviews, and then once I am in a job there's perhaps the social side of things. I mean it's not so bad in this job because I've got on quite well, because I think may be the talking on the phone has brought me out of myself a bit. But in previous jobs, practically every time I've had a briefing or a meeting with a manager, or appraisal that sort of thing it's always been, "You're doing the job very well, but you're very, very quiet". You're too quiet or you don't talk enough, or whatever.	Social side of work a difficulty Putting myself across at interviews a difficulty Social difficulties once in job Got on quite well socially in this job Talking on the phone has brought me out of myself Briefings Meeting with managers Appraisal Appraised as 'doing the job well but very quiet' Not talking enough perceived as difficulty
I	And do you think they sort of appraise you negatively because of that?	
R	Yeah, I think they quite often tend to, and I think when you've got people who are autistic	Appraised negatively as quiet ASD tend not to be talkative

	they might not be very talkative, especially if they've got a job to do then they're likely to be doing the job.	ASD likely to be doing the job, rather than talking
I	And do you feel that's an issue in your current…?	
R	No, not at all, because it just isn't. Like I say, I don't know whether it's talking on the phone that's made me a bit more talkative, or what but it just isn't. But, plus it's the sort of job where you are on the phone, so you don't actually have the opportunity too much.	Socialisation not an issue in current job Finding it easier to be talkative in current job Talking on the phone made me more talkative Don't have the opportunity to talk much
I	Yeah. Did the sort of the caseworker from [support agency] do any work around social skills or social confidence with you at all?	
R	We did some work on interview techniques and skills. He did arrange some normal interviews as well.	ASD employment agency did work on interview skills/technique ASD employment agency arranged some normal interviews
I	Like practice ones, or actually…	
R	For a sort of practice. Well I actual real interviews for real jobs, but he did sort of practice scenarios with me and stuff. But not a huge great deal, no.	Real interviews for real jobs Support worker did practice scenarios Not great deal of interview practice
I	And were those practice scenarios, were they useful?	
R	Yes, they were and they weren't. I mean it's one of those things where I think with interviews where you can do a lot of practice scenarios, but you may find that it all goes out of the window when you get to the real thing. But they were helpful I suppose.	Practice interviews varied in usefulness Practice interviews may go out window for real thing Practice interviews were helpful
I	Would it have been helpful for you to have received more help around sort of social issues, do you think?	

R	I'm not so sure, because the last job I was in before this... It was whilst I was in that job I think that… Yeah, it was, that I got the diagnosis, before then there wasn't a diagnosis there, so I don't really have anything to measure it against too much, it is only really this job. And I'm getting on fine with this job and the people in it.	Not sure if support on social issues would be helpful Got diagnosis during last job No diagnosis, so nothing to measure socialisation against Diagnosis related to social difficulties Getting on fine in this job and the people in it
I	Did… are people at work aware of your diagnosis?	
R	Yes, most.	Most people at work aware of diagnosis
I	Most. And you think that's a beneficial thing, or a difficult thing?	
R	No, I think it's reasonably beneficial. I don't think anyone treats me adversely or anything for it.	Beneficial colleagues aware of diagnosis No one treats me adversely because of diagnosis
I	Yeah, so what's beneficial about it, do you think?	
R	I think they're just aware a bit more of the fact that I might not talk and when I do talk I might, I sometimes might go on a bit. So they don't ask so much, or they don't comment too much about it if I am quiet sometimes or whatever.	Colleagues aware I might not talk Colleagues aware I might go on a bit Colleagues don't ask/comment if I am quiet
I	Yeah, okay. Are there any other sort of advantages or disadvantages, do you think, to having a diagnosis and… or for you what's changed since you've got your diagnosis?	
R	I think it's explained a lot of things, it's made me feel okay even on… I don't know if happy is the word, but a bit more content. And it's made me feel, in some ways, less concerned or less worried because it's answered a lot of questions. It's like I'm not just a freak, there's a reason for it, is the sort of feeling I got since	Diagnosis has explained a lot Diagnosis made me feel more content Diagnosis made me less concerned/worried Diagnosis answered lots of questions Reason for being a 'freak' Diagnosis

my diagnosis.	
I Did you feel you were treated as a freak?	
R Sometimes, but more often I just sort of kept myself to myself a bit too much, so I couldn't really say whether I was treated… what I was treated like, because I wasn't really in society to be treated. *[Telephone rings]*	Sometimes treated as a freak Kept myself to myself too much Wasn't really in society / removed self from society
[Respondent leaves to answer telephone]	
I And so, sorry, we were just, we were talking about your diagnosis, weren't we? And whether that had been a beneficial thing or not, but you *[?22:29 overlapping dialogue]*?	
R I think so, yes. So sometimes I do sort of feel a bit sort of annoyed that it didn't come earlier, and I wonder what it would have been like had it been earlier. Not just from a work perspective, but socially, if I'd have been able to go through a lot of the things that are available to sort of children and teenagers with Asperger's now. And whether life would have been different and I would have made different choices, and done things differently. But then sometimes I also feel that if it had come too early, there's a tendency with this sort of thing to over compensate. To sort of perhaps say it's not his fault he's got Asperger's, or to not sort of push yourself out into the world or whatever. Whereas, growing up I did not have the choice, because it wasn't… I couldn't really turn around and say I'm autistic, or whatever.	Diagnosis beneficial Annoyed diagnosis not earlier Wonder about impact if earlier diagnosis Diagnosis gives access to support More support available for children and teenagers with diagnosis Diagnosis would have made different life Diagnosis gives access to choices Diagnosis leads to tendency to over-compensate Diagnosis can shift blame from individual Diagnosis can lead you to not push self No diagnosis limited choice
I Yeah, so there's advantages and disadvantages?	
R Advantages to the diagnosis and depending on	Advantages of diagnosis varies depending on age

	when you get it.	
I	Yeah, and you might not have gone and got your sort of the jobs you were talking about?	
R	Yeah, or I might have chosen a different path at university, or whatever.	Might have chosen different path if had diagnosis
I	In terms of the… Your first point was that you wish, or perhaps sometimes you wish the diagnosis had come earlier so that you could access services that some kids, etc., who get a diagnosis access. What sort of services would you want to access, do you think?	
R	It's less so now, because I've sort of pushed my way through it and learnt my way through it in other ways. But at the time I would say things like social skills in a big way, developing, maintaining friendships, relationships. Especially at that sort of teenage age when they stop being just sort of children playing, and sort of developing to sort of more teenagers and mature sort of friendships and relationships.	Need less services now Pushed myself and learnt without diagnosis Social skills would have been useful Social skills would have been useful during teenage years Teens, develop more mature relationships, not just play
I	Yeah, okay. And I suppose that might have been beneficial in terms of work as well with that specific…?	
R	Yeah, as well, because if you're more confident and better able socially with friends, presumably you'd be better able in work scenarios and interviews and things.	Social skills useful in work Social skills lead to confidence Social skills improve work scenarios and interview performance

F. Andrew	
I Okay. When you've been out of work and are looking for work, what is it that you found most difficult about that?	
R I suppose before I had a number of jobs, applying for them and then not getting a response. If they're not going to give you a job, it's better to at least know that you're not going to get a job, 'cos otherwise you've got like a false sense of hope. I mean if you're not going to get a job, fair enough, they should at least tell you. Right, you're not going to get the job. Well some of them did, but most of them don't. So if you don't know what's wrong, then you can't really adjust, so…	Applying for jobs and not getting response a difficulty Better to know if not getting a job False sense of hope if not informed about job Fair enough if unsuccessful, but they should tell you Minority of employers don't tell you if unsuccessful Need feedback from applications so know what to adjust
I Yeah. So you want the feedback from them so that you can adjust?	
R Yeah.	Want feedback so can adjust
I Do you think it's easy to adjust?	
R Well it depends, 'cos I wondered when they got back to me and that was in 2007 that applied for a computer technician job. I did good and everything, except they said I didn't come across as that confident, even though I could have easily done it, the work, I just didn't project. But that was that strange because it was like a very small room, probably not much bigger than this around a table about this size. And I was just sort of sat here and around a table with all these different women, like there was about five different women interviewing me in like a cramped room.	Applied for computer technician job Did good at application / interview but lacked confidence Could have easily done the job Didn't project confidence Interview in small room Interview around table with all these different women 5 women interviewing me in a cramped room was strange
I Yeah, so it was a bit of an odd experience?	
R Yeah, especially when you've never met any of	

	them as well.	Never having met interviewers made it stranger
I	Do you think that… but you think that you would have been perfectly able to do that job?	
R	Yeah, I do, if necessary, yeah. They said my references were perfectly acceptable, it's just the confidence thing that didn't come across.	Perfectly able to do job References perfectly acceptable Confidence didn't come across in interview
I	And do you think that that apparent sort of lack of confidence, I mean did you feel that you lacked confidence in that situation?	
R	Not really.	Didn't feel lacked confidence in interview despite this being perceived by interviewers
I	No?	
R	It might be just... I was mumbling, probably like I'm doing now.	Mumbling in interview
I	I think you're speaking absolutely fine.	
R	Well, because like by the tone it doesn't [?19:06] like that [?19:06] my voice though, but it just comes out that way.	Voice lacks tonal variation
I	And is that, do you think that's something that you associate with Asperger's in some way?	
R	I don't know 'cos some people with Asperger's they've got more, more tone and pitch than I do. So may be…	Some people with AS have more vocal tone and pitch
I	Right, so you're not sure whether that's just sort of part of you, or part of Asperger's?	
R	When I was younger I used to sing in the choir and my voice was quite good. So may be it's because of puberty, or may be it's because of trauma, or may be it's because of whatever.	Sang in choir when younger Lost tone/pitch following puberty / trauma
I	Right, okay.	
R	But, yeah, it's not as [?19:38]. More bland	Voice more bland now

	now, my voice.	
I	But either way, for you, that sort of interview process was a barrier to actually getting the job which you knew you could do?	
R	Yeah.	Interview process as barrier
I	Yeah, okay. What other sort of barriers do you think there are that… in terms of you being able to access work, either go through the sort of recruitment phase, or maintain a job which might be related to sort of Asperger's as a condition, or symptoms associated with it?	
R	I'm not sure, when I did my CV some people have complained it's hard to read. But I can read it and it is, these are your ten points, you know, because some of the people interviewing you are older, or wearing glasses and they can't read it. So I can't imagine like why if I can read it, why can't they read? That's probably a bit…	People have complained CV is hard to read Can't read CV as older / glasses wearers Can't imagine why they can't read CV if I can
I	What, they were saying the type was too small?	
R	Yeah, but if I could read it, so I thought like why can't they read it? I mean you've got glasses, so… I mean that's quite reasonable that size there, but mine might have been a bit smaller, 'cos I put quite a bit of text on it and I wanted it all to fit on a few pages.	Font too small on CV Why can't they read CV if have glasses!? Font was reasonable size Font smaller so could fit text on a few pages
I	I see, so you made the text small so that it would fit in the…	
R	But it wasn't ridiculously small, it wasn't, it wasn't much smaller than this, but I suppose because it was dense as well. You know, there's like a big wall of text there.	Font wasn't ridiculously small Text on CV was small and dense, big wall of text

G. Frank

I	And what support do you receive whilst you are there?	
R	Well the first day I went with [name J] who is someone who works there. Then she… after about an hour she left me to it, because I was fine with what I was doing. And they come and visit me… I think two or three times every day, so it is very good. Yeah.	First day worked with specific staff Staff left me to it after an hour Left as fine with what I was doing Support staff visit 2/3 times a day Support is very good
I	And those… What's the sort of content of those visits? How do those visits work?	
R	It is just general to see how I am doing… They ask me if I am okay. Just check what I am doing.	Work visits to see how I'm doing Support staff check I'm OK Support staff check what I'm doing
I	Have you ever needed them to do anything? Have they ever been able to help out with difficulties at work?	
R	Well the first day [name J] helped me, she showed me what to do once. [?7.58]	Help on first day Shown what to do once
I	Yeah.	
R	That was useful.	Useful to be shown what to do
I	Yeah.	
R	Other than that I have been fine.	Not needed support other than first day
I	So literally, sort of when the come and visit you two or three times during the day it is normally just/	
R	Just checking up on me to see if I am okay.	2/3 visits a day checking OK
I	And then things are generally absolutely fine.	
R	Yeah. It has been fine. Yes.	Work has been fine
I	What sort of… Within that job in [M] what are	

	the sort of challenges you face?	
		All day on spreadsheets
R	Well it is all day on spreadsheets basically. What I am doing is correcting data on the spreadsheets. It is… I am fine doing it, but the thing is I am doing it all day so it gets a bit tiresome just staring at the screen all day. Because it is just the same thing all day.	Correct data on spreadsheets Fine doing work but gets tiresome Staring at the screen all day Same thing all day is tiresome
I	Tiresome in terms of it being boring or it being physical difficult?	
R	Well boring. And also that strain on your eyes can be a bit… The thing is I been going outside taking breaks because… And I don't like just walking out and leaving it, because it is a bit… So I have got an hour each day, but I usually only take half an hour for lunch and that's it.	Boring work Strain on eyes (computer work) Going outside for breaks Don't like taking breaks, leaving work Usually take half hour for lunch, out of hour allowance
I	Why do you think that is?	
R	Well the thing is if I leave the building, I have to ask reception to get back in, so it is a bit of a performance because there is pass you need to get back in. And I haven't got one of those because I am only part time. I just don't leaving things.	Have to ask reception to get back into building Asking reception is a bit of a performance Need a pass to get back into building Haven't got pass as only part-time Don't like leaving things
I	But is that because you have to ask reception or because you sort of feel bad that you have taken breaks.	
R	I do feel bad just walking out. Yeah. I don't know why that it is but I just… It is a lot harder walking and leaving what I doing.	Feel bad just walking out Hard walking out and leaving what I'm doing
I	Is that because of sort of pressures you put on yourself? Or because you are worried what your boss might think or?	
R	No I put it on myself really I think. Because I	Put pressure on myself Boss wouldn't mind if take breaks

	know she wouldn't really mind but it is just… I just want to do well.	Want to do well at work
I	In terms of asking reception to get back in, because you said yourself you are a bit shy talking to people, is that something else which might/	
R	Yeah. I prefer not to do like… Yes. But I did have a word with [name G] about that this morning, and I think she is trying for me to get a pass for those two days or whatever so…	Don't like to ask reception to get back in Spoke to support staff about difficulty asking Support staff trying to get pass
I	So when you have got difficulties like that at work then you feel you've got the support here.	Feel supported by support staff
R	Yes.	
I	In terms of where you see the future going, how would you like… I suppose in terms of employment how would you like that to progress?	
R	Well I would like to get a full time paid job eventually. But I don't think I am anywhere near that now but…	Would like a full time paid job eventually Not anywhere near full time paid work currently

H. Jane

I	But [retail] was the first successful one?	Current job was first successful application
R	Yes.	
I	And you had interviews for the other three did you?	
R	Yes.	Interviews for all previous applications
I	But you weren't successful at those?	
R	No.	Not successful at 3 interviews
I	Why do you think that was? What was hardest for you in the interviews?	
R	Like talking to people at the same… you know, it is like… it might make confidence seem like… It can be quite hard. It is like, for the [stationers] one it was like a group interview, like twelve people. And it is like you have to do figure it out together, like team work, and of course I have never done that before.	Talking to people as barrier to interviews Confidence as barrier to interviews Interviews as hard Had group interview of 12 Had to figure out group task Had to team work at group interview Never done team work before
I	Yeah.	
R	It is like they shove you into something and really like… When they phoned you up like they… they really should have told you.	They shove you into things in interview Should have told group task when offered interview
I	Right. That there was team work involved.	
R	Yeah. Because it is like… I've never done a group interview before, they didn't tell you that when they phoned you up.	Should have told me it was a group interview Didn't tell you it was a group interview
I	Is that something that made it particularly difficult for you?	
R	Yeah.	Group interview was difficult
I	And what about team work, is that something which is difficult for you?	
R	No. I am good with that, working with others.	Good at team work / working with others
I	And you are good with that now… is that something you've learnt through… How did	

	you learn that?	
R	I've learnt that when I've been at the college like getting [?14.35]. Because when I was at [C] and [EH] I… all of my friends were there so I know them like… and then after I made like more friends now. And after I got to know people there.	Learnt team work at college All my friends were at college Made more friends since college Got to know people
I	So your friends have been a big support for you as well?	
R	Yes.	Friends have been big support
I	What other sources of support have you had?	
R	What's that… Sorry!	
I	Like what other sources of support have you had like in terms of family or other groups that you've been to?	
R	Well they just help er… It is like they always ask if you need anything like, you can like talk to them and that?	Support / friends always available to ask Can talk to support / friends
I	Who?	
R	Like [E and Y – support agency staff].	ASD employment support always available
I	So the [support agency] has been the most sort of important thing in your transition to work.	
R	Yes.	ASD employment support most important in transition
I	So they… It sounds like you are saying it is good they are around and you can always… They are approachable and you can always ask them questions.	
R	Yes.	Good that ASD employment support always available
I	Is there anything else that they do which is particularly good. You mentioned help with interviews, help with CVs, support on the job. Is there anything which you can think of, which is really good?	
R	No. Not really.	

I. Jade	
I /at twenty one. Okay. So you got additional support prior to your diagnosis, before your…/	
R After my diagnosis.	
I /Okay, only after your diagnosis. Okay. Erm… And did you get any support at college around sort of skills, work skills, or looking to sort of find jobs after college?	Support after diagnosis
R I did an IT course, and we did do a unit on work for employment.	Did an IT course at college useful Work for employment unit at college useful
I Yeah. And was that useful?	
R That was useful, yeah.	
I How was it useful? What was useful about it?	
R Because we did mock interviews.	Mock interviews were useful
I Okay.	
R And went to different places, and…	Went to different places
I Yeah. And that's something you found/	
R Useful, yeah.	Going to different places useful
I /most useful. Was there anything which wasn't in that support that you got that you would have liked to have had?	
R There isn't anything, no.	Nothing missed from support package
I No, nothing? Okay. So did… how did you come to [ASD support agency]?	
R I was having one to one support at college.	One to one support at college access support
I Okay.	
R Where somebody called [name J] er… And I	

	was telling her about my… how I wanted to get into work.	Told someone at college wanted to get into work
I	Yeah.	
R	So… And then she put me in touch with [name NB].	College contact put in touch with ASD employment support
I	Right.	
R	And that's how I got to come here.	
I	Okay. And is this before your diagnosis, or…?	
R	This is after.	Access to ASD employment support after diagnosis
I	This is now after your diagnosis.	
R	Yeah.	
I	So you wouldn't have been able to come here without your diagnosis?	
R	No.	No access to support agency without diagnosis
I	Okay. And how… how long have you been coming here then?	
R	About a year.	
I	About a year. Okay. And how… what's the process from sort of that start, a year ago, up to where you are now? How has your support changed?	ASD employment support for about a year
R	Well it is learning me into it, which is I want to do.	Support is learning me into it Support is providing me what I want
I	Yeah.	
R	I want to be able to work.	
I	Yeah. And are you in a… are you paid for the work you do at the moment, or is it a work placement?/	Want to be able to work
R	It's a work placement.	Work placement

I	/It's a work placement. So it's a voluntary, unpaid post?	
J. Bruce		
R	Yes. I'm working for a different… not the first one, but I'm working for the new one now that I'm working with now.	Working for supporting agency Changed jobs
I	Okay, I see.	
R	And this will be my fifth, sixth year coming now, with our new agency.	5 / 6 years with agency
I	Okay. So that… that agency, the agency that you're with at the moment, they supported you to find the supermarket work?	
R	Yeah. They're the same agency that found me the supermarket.	Agency has found a number of jobs
I	And now you're working for them directly?	
R	Yeah. Fully, yeah.	Now working for supporting agency directly
I	Fully. And what… how many hours a week do you work?	
R	I'm doing between fifteen, sixteen hour basics, plus if there's any overtime, I do a bit of overtime as well.	Work between 15 and 16 hours Do some overtime if available
I	Okay. And are you paid for that work?	
R	I am being paid, yes.	Being paid for work
I	Okay. And do you… if you work over sixteen hours a week does that affect any benefits that you might be on?	
R	No.	
I	Are you on any benefits at all?	
R	No.	Not on any benefits
I	No okay. So you rely on the income from work	

	in order to…	
R	Yes.	
I	To fund your lifestyle.	
R	Yeah.	Rely on income to fund lifestyle
I	Okay. What's the… the nature of the work that you do at the moment?	
R	Erm… My nature of work is working in the stock room, which is working in the back room with products. So a product can be handed out to customers.	Work in the stock room Work in the back room with products Enable product to be handed out to customers
I	Okay. And does that… does that job suit you? Do you enjoy it?	
R	Yes, it does. And the reason why it suits me is because it's a… it helps me communicate with a colleague in the back room as well, instead of being alone just by myself doing other stuff. I've got other people helping me out, as well as the agency [?who find] me the job. And I've also met nice people who can help me stay a bit longer with the agen-… with the company as well.	Enjoy / suit current job Job helps communicate with colleagues Prefer to work with colleague than alone Other people help Agency helps Agency helps find job Nice people help me stay longer with company
I	Okay. I see. So… so it sounds like you get social support on the job that you're doing.	
R	Yeah.	
I	Yeah. Erm… Is that something you've always had since you've worked there, or have you had to build that up?	Social support on the job
R	At first it was difficult, because I was a [?temp at] first. So I had to make my own way there, make my own way to get the attention [?or that] I need more help.	Socialisation was difficult at first Temp work made it difficult to socialise Had to make own way

I	Yeah.	Had to work out how to get more help at work
R	[?But then I was just]… after two years that's when I got the permanent job, and that's when everybody began to help me understand how things work in the stock room, and how the job is to be done.	Got permanent job after 2 years Everybody helped when I got permanent job Others explained how job is done / how things work
I	Okay. So now you're there permanently it sounds like you get a lot of support from within that company itself.	
R	I do.	
I	Do you still have support from the agency that supported you to find that job initially?	Lots of support from within the company, once permanent work
R	I do get support probably about six to… maybe coming up to two months, at least, but I do get it now and again, and not a right lot as I used to have.	Still get support from ASD support agency No support for approx 2 months Less support than used to have
I	Okay. And is that erm… is that something that you see as a good thing?	
R	Yeah. Because the agency says to me if I need any help, that if there's anything that I'm struggling with, or I don't… I'm not sure, to go to the agency as well as going to the company, in case I'm not unsure.	Reduced support is a good thing Agency available if have difficulty Unsure where to go if struggling Company available if have difficulty
I	Okay. And you're happy with that offer?	
R	Yeah.	
I	Is there anything else that you wish they could do, or you think they should do differently in order to improve your experience?	Happy agency is still available if struggling
R	Er… No. All the support that they give me is absolutely alright.	
		Support received is absolutely right

Appendix 9. Example of theme development

The finalised theme of Transition Support is provided below (Excerpt 4), as well as information to illustrate how this theme developed through the analysis. Excerpt 1 provides a sample of the code list derived from the participant transcripts. Following this, Excerpts 2 and 3 provide samples of the thematic groupings at different stages during the analysis. These data samples have been provided to best illustrate the process of analysis and are not an exhaustive or comprehensive representation of this. A process diagram is provided below in order to clarify how some of the subthemes may have developed and how codes may have moved between different groupings throughout the analysis:
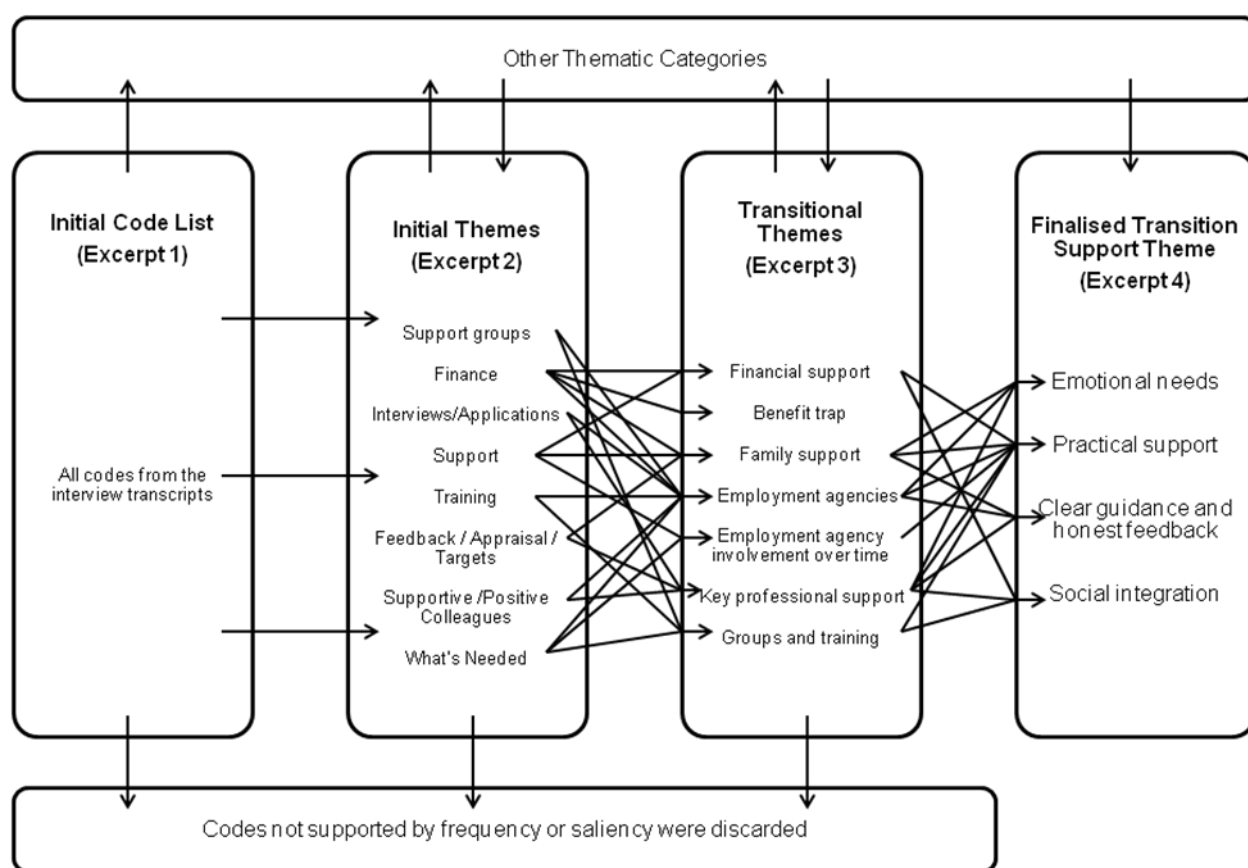
Arrows represent the flow of codes between different thematic categories at different stages of the analysis. Neither all of the 'codes flows', or thematic categories have been represented, in order that a simplified diagram can be provided to illustrate the inter-related complexity of relationships between different themes at different stages of the analysis.

Excerpt 1. Code list

A sample from the original code list derived from the interview transcripts is provided. This comprised many pages of raw data and was sorted alphabetically, with duplicated codes from same participants removed in order to facilitate initial semantic grouping of the codes.

Help and recognition since diagnosis

Help job searching

Help on first day

Help with CVs on courses not useful

helped colleagues

Helped friend by working

Helpful if staff could give reference

High level of support due to funding

Higher benefit levels for people with permanent conditions like ASD

History of failed placement

Honest feedback more important than feelings

Hope for change in the benefits system

Hope for more hours following review

Hopelessness

Hours dropped to 6 a day

Hours of personal assistance

How much budget left over

How personal budget works when you have skills / work?

Humiliated

I can eat healthily

I do everything all right, otherwise they tell me

I don't pick up cues or socialise

I don't see things

I had a secret admirer, confusing

I helped colleagues

I see everything

I won't get a hearing

I would change the way benefits are paid out

I'm a target and a box to tick

I'm prepared for work

I'm somebody's responsibility

Identified main barriers with staff

Identified strengths

Identified what I was looking for

Identify strengths and weaknesses on own and by feedback from others

If I earn money, lose benefit

If not specifically invited assume 'shunned'

If personality is great you will achieve

If too much work, lose benefit

If uncomfortable with promotion would want option to go back

If you're in work the schemes exist

Ignorance about AS

Ignoring the pain leads to extra psychological problems

Impact of diagnosis

Impact on other staff productivity

Important to improve communication with others

Impressed with model of support

Improving understanding of AS helps marginally

In my own world

Increased awareness

Increasing freedom as support reduces

Increasing staff awareness

Influence of government policy on ASD and DWP

Informal meeting with support agency

Information from sessions / training providers

Information from staff member

Input was 18-24 months ago

Intelligent

Interacting with new people is the problem

Interacting with new people makes anxious

Interacting with people can be a difficulty

Interpret things differently

Interview around table with all these different women

Interview as biggest barrier

Interview as problem

Interview in small room

Interview just a few questions

Interview process as barrier

Interview role play was useful

Interview support most useful

Interview; just wanted to meet me

Interviewed about type of work wanted

Interviews for all previous applications

Involved with other employment agency previously

It's important people fit in

Job / wage subsidy available

Job at support agency would be good

Job becomes hobby

Job Centre

Job Centre

Job Centre and non-specific agency helped understand advice

Job Centre delay not helpful

Job Centre do nothing for me

Job Centre have machines to help look for jobs

Job Centre info lacked clarity

Job Centre involvement was very useful

Job Centre is most depressing place in the country

Job Centre not helpful

Job Centre not helpful at all

Job centre opinion

Job Centre provided info, lacked clarity

Job Centre recognition

Job Centre referred to ASD support agency

Job Centre send you to organisation

Job Centre sending for job searches was useful

Job Centre sends you on training courses

Job Centre sent to Action for Employment

Job Centre should ask if we need help

Job Centre should give more advice

Job Centre slow in putting me forward for programmes

Job Centre system screwed up

Job Centre was useful

Job helps communicate with colleagues

Job needs to mean financially better off and stability

Job needs to separate from hobby, to not ruin

Job not close

Job search on the computer

Job search scheme

Job search support is pointless

Job seekers allowance

Job title

Job title means status and dignity

Job would give me something to do

Jobs aren't changing

Jobseekers

Joined readers group

Just a social group

Just enjoy I'm doing something

Just got on with job, despite lights

Just left to get on with it

Just sign things at Job Centre then go

Keep network secure

Keep on working towards goal

Keep options open

Keep shelves stocked and well presented

Kept myself to myself too much

Kept record / reference of answer

Key support individuals

Known I was different since 12 or 13

Lack of info on CV

Lack of recognition as a barrier

Lack of recognition of ASD by employer would cause big problems

Lack of replies to applications

Lack of shared interest in the group

Lack of support would lead to isolation

Lack of support would struggle to cope on own

Late finishes

Leaflet distribution for 2 weeks; boring

Learning more in current placement

Learnt to be more respectful and positive with others

Learnt to mimic behaviour

Left before made to

Left the job

Left work because finished studies

Less support than used to have

Letter confirmed diagnosis

Letters include, team player, good communicator and flexible, but I'm not

Level of residential care inappropriate

Life could have been different

Life skills programmes

Like a befriending scheme

Like being left to get on with work

Like getting things right

Like routine

Like to leave things where I last used them

Limited by finance

Limited funding for short courses

Limited job searching

Limited local job opportunities

Limited opportunities due to interests

Limited opportunities for people with AS

Limited support

Limits imposed on people with AS

Limits/constraints of benefits

Line manager has to monitor

Literal understanding; hard work socially

Live at home with Mum

Live close to Dad

Live with Mum

Live with Mum and Stepdad

Location of train station

Location of work close to staff important

Long time since previous employment

Long time to get diagnosis

Long weeks OK, because not constant

Longer wages subsidy better

Looking forward to appointment that got changed

Looking to work normally

Loss of cognitive abilities due to many emotional traumas

Loss of skills due to trauma

Lost communication in interview

Lost enthusiasm for volunteering

Lost for words = communication difficulty

Lost job as company fired all agency staff

Lost time / opportunities

Lost tone/pitch following puberty / trauma

Lots of different traumas over time

Lots of input from support staff

Lots of jobs are target driven

Lots of jobs set time limits

Lots of other more viable employees

Lots of qualifications

Lots of services for children

Lots of support from within the company, once permanent work

Lottery funded

Low level for temporary disability

Lower paid when younger

Lower payments for temporary mental health issues

Lower rate DLA

Luck if area of work interested in

Main advantage of diagnosis is access to the system

Main placement and backup

Mainly women in the group

Maintaining working relationships as difficulty

Make friends

Make sure arrive on time

Making me ill

Manage stock around the tills

Manage stock on JML stands

Manage to control anger at work

Manager doesn't have to monitor for others

Many people unemployed

Marketing dept work 2 days a month

May need a couple of hours weekly debrief

Medical at Job Centre

Medical does not focus enough on mental factors

Medicalised

Meeting people as a difficulty

Meeting with managers

Meetings with senior council officers

Member of a client group

Menial work boring, need a challenge

Mental illness not part of AS, completely separate

Met good people

Might have chosen different path if had diagnosis

Might kick back against bullying

Might try to reapply for benefits

Minority of employers don't tell you if unsuccessful

Misdiagnosis impact

Misjudge distances

Missed employment opportunities

Missed opportunities

Missing out if part time

Mis-use of AS to mean can't cope because mentally deficient

Mock interviews were useful

More attention to detail than other workers

More confident following transition

More difficult for others than for me

More important you can fit in than do the job

More like a therapy session

More ongoing support for first job / first job in a while

More or less full time in winter

More people with AS at support groups

More severe AS / ASD need support

More severe ASD deserve higher level payments

More shifts in winter months

More support available for children and teenagers with diagnosis

More support in different area

More support means more opportunity

More than job search

More thorough assessments needed

Most friends have jobs

Most important to recognise individuality of AS individuals

Most support groups down south

Mother thinking about future

Motivation

Moving towards goals

Much less services for late diagnosis

Mum always been there for me

Mum always moves stuff

Mum and aunt considered ASD

Mum and aunt suggested going for diagnosis

Mum and boyfriend take me to places

Mum didn't want me to go to mainstream school

Mum drives me

Mum felt retail would be too difficult

Mum helped a lot through school and college

Mum helped at agency

Mum helps me

Mum instigated seeking diagnosis

Mum involved with getting Social Worker to help

Mum is closer than anybody else

Mum is closest

Mum makes it hard for me to find things

Mum researched ASD

Mum supportive

Mum takes me to football

Mum thought mainstream school would be too hard

Mum throws stuff in a bin bag somewhere

Mum throws things away, doesn't actually tidy

Mum's knowledge of me growing up

Mumbled in interview

Mumbling in interview

Mundane or entry level jobs could be fascinating to me

Must qualify for payments

Natural lighting better

Navigating social issues as a difficult

Need a car for work

Need access to employers

Need access to key person

Need employer to take leap of faith

Need employer with personal experience of AS

Need feedback from applications so know what to adjust

Need feedback if work not good enough

Need for skills

Need to be more flexible or realistic about targets

Need to go beyond job search

Need to have job interested and passionate in

Need to show boss can do work

Needed course that would challenge me

Needs reliability / predictability to access services

Negative impact of mis-self-diagnosis on AS label

Negative impact of too much voluntary work

Negative medical model in group

Nervous about interview before

Nervous doing interview today

Nervous in interview

Neuropsychologist thought not AS, maybe schizotypal

Never having met interviewers made it stranger

Never heard back re applications

Never talked to anyone

New level of payment structure

New people difficulty in routine

New placements start few hours and build up

New work placements through Job Centre useful

NHS suspected Huntingdon's first and maybe AS

NHS works so slowly

Nice and Relaxed group

Nice that support agency helps

Nice venue for group[

No access to support agency without diagnosis

No ASD diagnosis at school

No benefit at all

No confidence building work

No constant support now

No deadlines, just never-ending work

No desire to go for therapy

No diagnosis when finished school

No difference between diagnosis or not

No difficulties in work roles

No difficulties once got job

No difficulties with job

No difficulties with public transport

No difficulty maintaining employment

No dress sense

No driving licence

No guarantee group will run

No ideas for improving support

No interest in fixing computers, do it because I can

No interview for current job

No job at present

No local support groups

No money to pay

No one willing to help financially

No opportunity for unpaid work

No opportunity for voluntary work

No other support needed

No problems getting up in the morning

No progress

No really bad aspects of support

No rigid pattern (lates/earlys) in shifts as advantage

No services specifically for late diagnosis AS

No shared experiences

No support / social groups accessed

No support for approx 2 months

Nobody listens to me

Non-specific support agency helped understand Job Centre info

Not able to cope

Not able to explain to others

Not able to request references from long time ago

Not able to work weekends as see family

Not all placements enjoyable

Not anxious about working or applying

Not anywhere near full time paid work currently

Not applied for apprenticeships

Not AS specific support

Not attended any groups

Not been to group for a year

Not better off through working

Not bothered about the pay

Not capable of full-time straight away

Not confident talking to people

Not disabled do not qualify for payments

Not discussed future goals with ASD employment support

Not doing overtime at the start

Not eligible for benefits

Not enough hours to stay

Not feel confident enough

Not flexible, good communicator or team player

Not found anything difficult

Not good answering the phone

Not good on public transport

Not great deal of interview practice

Not interested in casual conversation

Not just a social group

Not just wages

Not much hope of future benefit given current policy / economics

Not needed support other than first day

Not on any benefits

Not paid

Not paid for voluntary work

Not paid work

Not physically disabled

Not ready for more work at the moment

Not struggled in any job to date

Not successful at 3 interviews

Not supported by any other agency previously

Not sure how to build confidence faster

Not sure how to improve support

Not sure how to improve support

Not sure how to improve support

Not sure if need support

Not sure if support agency will arrange progression

Not sure what additional support is needed

Not sure where need support

Not surprised by diagnosis

Not talking enough perceived as difficulty

Nothing about the work is hard

Nothing agency could have done differently

Nothing ASD employment support could do differently

Nothing I would have changed in support

Nothing missed from support package

Notice all the flickering from lights

Obsessed with written word

Occasional support from staff

Offices often have enough daylight without needing lights

OK that ask colleagues for support

On Job Seekers

On my own in my own world

One main placement, one backup

One person at Job Centre

One to one support from ASD employment support agency

Only interested in certain areas of law

Opinion had AS from others

Opportunity for overtime

Opportunity to prove can do work

Option for 40-50 hour weeks in snow/winter

Organisational contradiction

Organisational skills

Other benefits would also stop

Other disabilities have different implications on ability to work

Other group members in and out of work

Other people help

Other workers started late

Other workers take more calls under pressure

Others annoyed if I show them up by working harder / better

Others attached to support worker

Others don't notice strip lights

Others explained how job is done / how things work

Others filter out and focus vision more easily

Others misuse label of AS to cover up personal deficits

Others not happy I stuck to job description

Others won't like change to their working environment

A sample of some initial thematic grouping of codes related to transition support is provided.

Support Groups	Anger group in other specialists and support units
	Anger group separate from work
	AS Group moved from hospital to a pub
	AS Women's group as useful to transition / work
	AS women's group was useful
	Aspergers in the group
	Associated with such people
	Assumption support groups will be like training courses
	At least group was attempting to do something / influence strategy
	Attend 2 different groups
	Attended AS women's group
	Attended ASD employment programme
	Attended group
	Attending group for 2 years
	Communication support groups help work
	Could be honest in small group
	Could have all had AS
	Don't access social / support groups
	Don't attend AS Women's group any more
	Everyone in group had problem
	Gateway to work programme as a group
	Group
	Group - general stuff in world of work
	Group – rights for disabled people
	Group – what to do and not to do at work
	Group appeared to be more for ASD than AS
	Group attended was not appropriate
	Group did not feel right
	Group hit lots of points on the head
	Group interview was difficult
	Group involved with Autism Strategy
	Group is easy access from train station
	Group leader could relate
	Group leader had been in same boat
	Group more proactive
	Group run by students
	Group run by students during term time
	Group was helpful
	Group: social activities
	Groups / individuals often happy to be infantilised
	Groups need resources, rooms and funds
	Groups rely on variable funding
	Joined readers group
	Just a social group
	Lack of shared interest in the group
	Mainly women in the group
	More like a therapy session
	More people with AS at support groups
	Most support groups down south
	Negative medical model in group
	Nice and Relaxed group
	Nice venue for group[
	No desire to go for therapy
	No guarantee group will run
	No local support groups

	No support / social groups accessed
	Not attended any groups
	Not been to group for a year
	Not just a social group
	Other group members in and out of work
	Others from group are decent people
	Others in Gateway to Work struggled
	Others in group concerned with employment issues
	Others with Aspergers
	Over-skilled for training courses / groups
	PC to join group
	Positive social model in group
	Pre-selected group of similar people
	Readers group closed because of library cuts
	Returning to work group
	Self diagnosis as problem in the groups
	Small group better than large, couldn't cope
	Stopped attending AS women's group due to work
	Support groups should recognise having to sign on
	Support groups tend to be near city centres
	Suspect more had Aspergers
	Tried to get involved with voluntary groups
	Used to access group once a month
	Used to access groups
	Used to attend women's group at hospital
	Useful as met lots of people with AS
	Wanted to attend group
	Work placement clashes with group
	Would consider accessing support group
	Would like to see what support group is like
	Would still like to attend AS women's group
Finance	'Benefits trap'
	3 levels of benefits
	Acknowledgement payment structure may take time to perfect
	Affects benefits if work over 16 hours
	Applying for Incapacity and DLA, had to attend medical
	AS main reason applying for benefits
	ASD and AS should qualify for higher level payments, based on severity of disability
	ASD benefit entitlement
	ASD deserving of high level payments
	ASD employment support did not get involved in finance / benefits
	ASD included in off incapacity into work
	Avoid affecting payments while living with ASD
	Balance of wage with tax / NI etc
	Been assessed for benefits
	Being paid for work
	Benefit system confusing
	Benefit trap
	Benefits
	Benefits
	Benefits as life saver
	Benefits at risk from working
	Benefits do not cover cost of driving
	Benefits for a long time because of ASD
	Benefits removed
	Benefits stop if 16hours a week or more
	Benefits.
	Budgeting
	Can afford heating in winter
	Can get paid for pondering the universe if write a book

Can only work up to 16 hours

Can't work for nothing

Can't run a car on current part time wages

Clearer advice, rules and regulations on payments

Clearer info how payment affected by employment

Clearer rules on income support, housing, council tax, DLA and incapacity benefits

Constantly changing benefits and rules due to government

Contracted for 16 hours pw

Council or job centre would pay wage subsidy

Didn't care about money

Didn't go back as low paid

Didn't know was signing on

Difficult if social services support removed straight away

Disability benefit

DWP

Employment and support allowance

Employment subsidies

Employment support allowance

Employment Support Allowance

Employment support through agency

Expect minimum wage

Financially better off

Funding helps

Gaining a living

Get paid

Get paid work at Christmas

Get used to feeling of being paid

Going to agency as have to sign on

Got mobility benefit for arthritis, not for AS

Got to chase funding

Had to contribute to personal budget

Had to contribute towards lodging

Had to speak to funder

Higher benefit levels for people with permanent conditions like ASD

Hope for change in the benefits system

Hours of personal assistance

How much budget left over

How personal budget works when you have skills / work?

I can eat healthily

I would change the way benefits are paid out

If I earn money, lose benefit

If too much work, lose benefit

Job / wage subsidy available

Job needs to mean financially better off and stability

Jobseekers

Limited by finance

Limited funding for short courses

Limits/constraints of benefits

Longer wages subsidy better

Lower paid when younger

Lower payments for temporary mental health issues

Lower rate DLA

Might try to reapply for benefits

More severe ASD deserve higher level payments

Must qualify for payments

New level of payment structure

No benefit at all

No money to pay

No one willing to help financially

Not better off through working

	Not bothered about the pay
	Not disabled do not qualify for payments
	Not eligible for benefits
	Not just wages
	Not much hope of future benefit given current policy / economics
	Not on any benefits
	Not paid
	Not paid for voluntary work
	On Job Seekers
	Other benefits would also stop
	Paid work and benefits work out the same
	Paid work deducted from benefits
	Pay back money for course once earning
	Payment dependent on severity / need
	Permitted work
	Permitted work scheme
	Present leaders trying to get everybody off incapacity into work
	Problems when ESA introduced
	Receive all entitled benefits
	Receive DLA
	Receive income support
	Rely on income from work
	Rely on income to fund lifestyle
	Restricted by finances
	Restricted by funding processes
	Still get benefits with wage
	Still got to sign on
	Successful appeal, benefits reinstated
	Temporary benefits for temporary incapacity
	Temporary disability report to DWP regularly to enforce
	Total or partial wages subsidy
	Trying to figure out personal budget
	Trying to get the right benefits
	Understand benefits better now
	Understand difficulties with false benefit claims
	Understand it's not perfect
	Understand the process, not the data
	Understanding of the benefits
	Unsuccessful attempts to get advice on personal budget
	Want any job that pays the bills
	Want opportunity to earn £2000
	Want to be paid for current job
	Work between 15 and 16 hours
	Worse off if worked
	Would introduce 3 different benefit levels
	Would love to find job that pays the bills
	Wrong benefit
Interviews / Applications	5 women interviewing me in a cramped room was strange
	Able to put name as a reference
	Accepted job
	Already on a training course when could have applied to army
	Applied for 3 retail jobs
	Applied for a few jobs
	Applied for a job
	Applied for bar work
	Applied for computer technician job
	Applied for jobs
	Applied for retail jobs
	Applied to do retail first
	Applied to join army

	Apply for as many jobs as I can
	Applying for jobs and not getting response a difficulty
	Applying for work
	Approached company
	Arranging interviews most useful
	Avoiding normal interviews most useful
	Basically got job before interview
	Better to know if not getting a job
	Can't apply to army for 6 months following operation
	Can't provide references
	Can't read CV as older / glasses wearers
	Communication difficulty in interview
	Comparison to others who have secured work
	Concern of judgement re gaps in employment history
	Consider promotion when fully ready
	Determination important
	Develop networking is important
	Develop work-focussed assessments
	Did good at application / interview but lacked confidence
	Did well in army recruiting test
	Didn't feel lacked confidence in interview despite this being perceived by interviewers
	Didn't know where to go for work opportunities
	Didn't need Eng/Maths
	Didn't tell you it was a group interview
	Difference increasingly not accepted
	Difficulty finding info
	Don't like / do interviews
	Don't speak clearly in interviews
	Doors won't open for me
	Employment due to merit
	Enquire about job
	Fair enough if unsuccessful, but they should tell you
	False claim of communication skills and team player
	False sense of hope if not informed about job
	Faster employment process would increase motivation
	Feedback on CV
	Find jobs through networking and contacts
	Finding a job is hardest
	Finding job is the hardest part
	First CV was bad
	Font smaller so could fit text on a few pages
	Font too small on CV
	Font was reasonable size
	Font wasn't ridiculously small
	Get job
	Getting the job in the first place is the barrier
	Gone around asking for jobs
	Had four interviews previously
	Had group interview of 12
	Had interview practice, useful in confidence
	Had to figure out group task
	Had to meet with placement provider
	Had to team work at group interview
	Hard to find a job at first
	Hardest thing is finding a job
	Help with CVs on courses not useful
	Honest feedback more important than feelings
	I'm a target and a box to tick
	Interview around table with all these different women
	Interview as biggest barrier

Interview as problem

Interview in small room

Interview just a few questions

Interview process as barrier

Interview role play was useful

Interview support most useful

Interview; just wanted to meet me

Interviewed about type of work wanted

Interviews for all previous applications

Jobs aren't changing

Keep options open

Kept record / reference of answer

Lack of info on CV

Lack of replies to applications

Letters include, team player, good communicator and flexible, but i'm not

Limited opportunities due to interests

Long time since previous employment

Lost communication in interview

Lots of other more viable employees

Luck if area of work interested in

Minority of employers don't tell you if unsuccessful

Missed employment opportunities

Missed opportunities

Mock interviews were useful

Mumbled in interview

Mumbling in interview

Nervous about interview before

Nervous doing interview today

Nervous in interview

Never having met interviewers made it stranger

Never heard back re applications

No interview for current job

No opportunity for unpaid work

No progress

Not able to request references from long time ago

Not anxious about working or applying

Not applied for apprenticeships

Not great deal of interview practice

Not successful at 3 interviews

Opportunity to prove can do work

Opportunity to prove could do job

People have complained CV is hard to read

People will think worst due to lack of history

Persistence applying

Phoned with details of a project

Plan to send letters to employers being honest about AS

Practice interview hour before real interview

Practice interview was useful

Practice interview with support staff

Practice interviews may go out window for real thing

Practice interviews varied in usefulness

Practice interviews were helpful

Pre-employment requirements

Putting myself across at interviews a difficulty

Real interviews for real jobs

References perfectly acceptable

Role play interviews to get you to know what to do

Said to key person wanted job

Second CV was much better

Send letters out

	Should have told group task when offered interview
	Should have told me it was a group interview
	Six month trial
	Society needs explanation for age and lack of job
	Struggle to find employment
	Struggle to find me work placement
	Support going to interviews
	Talking to people as barrier to interviews
	Task focussed assessment
	Team player on every job description
	Telephone and conversation practice was useful
	Tell me same thing over and over
	Text on CV was small and dense, big wall of text
	They shove you into things in interview
	Too old for apprenticeships
	Tried to go self employed
	Tried to pursue work
	Trust in apprenticeships
	Try and find jobs for you
	Try to update CV
	Unsure what CV should look like
	Use of employment agency
	Waiting for application responses
	Want feedback so can adjust
	Want taste of what really would like to do
	Wanted lots of information on CV without having a dozen pages
	Went for job interview
	Why can't they read CV if have glasses!?
	Working interview involved training then job trial
	Working interview preferable
	Would find it difficult to work out what to apply for alone
Job Search	Didn't need job search
	Help job searching
	Job search on the computer
	Job search scheme
	Job search support is pointless
	Limited job searching
	Limited local job opportunities
	Limited opportunities for people with AS
	More than job search
	Paper always has same jobs
	Same jobs in paper throughout the week
	Searching for a job
	Was meant to do job searches but didn't
Job Centre	Always different person at job centre
	Conflict with Job centre
	Go to Job Centre
	Job Centre
	Job Centre
	Job Centre and non-specific agency helped understand advice
	Job Centre delay not helpful
	Job Centre do nothing for me
	Job Centre have machines to help look for jobs
	Job Centre info lacked clarity
	Job Centre involvement was very useful
	Job Centre is most depressing place in the country
	Job Centre not helpful
	Job Centre not helpful at all
	Job centre opinion
	Job Centre provided info, lacked clarity

	Job Centre recognition	
	Job Centre referred to ASD support agency	
	Job Centre send you to organisation	
	Job Centre sending for job searches was useful	
	Job Centre sends you on training courses	
	Job Centre sent to Action for Employment	
	Job Centre should ask if we need help	
	Job Centre should give more advice	
	Job Centre slow in putting me forward for programmes	
	Job Centre system screwed up	
	Job Centre was useful	
	Just sign things at Job Centre then go	
	Medical at Job Centre	
	New work placements through Job Centre useful	
	One person at Job Centre	
	Out of work, going to the job Centre	
	Problem with Job Centre	
Support	1 to 1 help me	
	1 to 1 residential support	
	1 to 1 skills support on placement	
	1 to 1 staff support	
	1 to 1 support	
	1 to 1 support at college	
	1 to 1 support at school	
	1 to 1 support from many support agencies	
	2/3 visits a day checking OK	
	5 / 6 years with agency	
	6 hours one day a week with social services	
	Advocate would be useful if had job	
	Advocate could approach and contact employers	
	Advocate to explain to staff	
	Advocate to go along to potential employers	
	Advocates are needed	
	Advocates would get a hearing	
	Agencies meeting process targets	
	Agencies playing the system	
	Agency asked if interested	
	Agency asked what sort of work looking for	
	Agency available if have difficulty	
	Agency believes ASD diagnosis	
	Agency did not contact me	
	Agency got placement at blind charity	
	Agency has found a number of jobs	
	Agency helps	
	Agency helps find job	
	Agency helps people into work	
	Agency provided general support into world of work	
	All charities / support agencies perform a similar role	
	All charities support in all areas	
	Also with skills support	
	Always support staff in the office when working	
	Arranged working interview, rather than normal interview	
	Arranging interviews most useful	
	ASD agency found me work placement	
	ASD agency staff did not find me placement	
	ASD employment agency arranged some normal interviews	
	ASD employment agency did work on interview skills/technique	
	ASD employment support accepting	
	ASD employment support agency	
	ASD employment support agency did not communicate	

	ASD employment support agency helped look for work
	ASD employment support agency needed to communicate
	ASD employment support agency needed to help with job search
	ASD employment support always been there
	ASD employment support available at request
	ASD employment support big help
	ASD employment support check once a day to check OK
	ASD employment support check to see if I'm OK
	ASD employment support did not get involved in finance / benefits
	ASD employment support feedback if doing things wrong
	ASD employment support for about a year
	ASD employment support help break things down
	ASD employment support help with CV
	ASD employment support help with interview
	ASD employment support help you put things right
	ASD employment support helped look for work
	ASD employment support most important in transition
	ASD employment support ongoing
	ASD employment support there if I get stuck
	ASD specific employment support
	ASD support agency always phone people to get work
	ASD support agency referral after diagnosis
	ASD support always helping people
	At another agency
	Avoiding normal interviews most useful
	Been supported by ASD employment agency for over a year
	Been through all support agencies over long time
	Before I did placements
	Break things down helps learn better
	Built up to full day working
	Can talk to support / friends
	Case worker arranged and oversaw everything
	Caseworker followed up after I started
	Charities mostly fulfil their role well
	Charities support independence and support
	Charities support overcoming barriers
	Come to ASD support agency to do job search
	Comfortable to approach agency for advice
	Company and agency know I always do my best at difficult times
	Constant support when started
	Contingency if placement not working
	Creating CV for first time
	Current support helps move towards independence
	Current support relatively cheap and safe
	Did not even get job search from ASD employment support
	Didn't need 1 to 1 previously
	Different support agency, long time ago
	Difficult to know whether support needed
	Discuss possible placement
	Do pretty much everything on my own
	Doing well = reduction in support
	Don't always get a placement / limited availability
	Don't need support now, work autonomously
	Don't need the support offered
	DWP not recognising ASD is problem for charities / support
	Employed by supporting agency
	Employed within ASD support agency
	Employers need to focus on strengths
	Encouragement to find more work
	Encouragement was good

Ended up with good support

Enjoy support received

Enjoyed work / support agency

Everybody helped when I got permanent job

Expectations of support from them

Feedback is given in nice supportive way

Finding work placement is best part of support

First day worked with specific staff

Found placement through agency

Found support agency fine first time

Get help for job

Good that ASD employment support always available

Good that support is reducing

Good to be given opportunities

Got reference from work placement

Got support

Got support most of day

Got whatever support needed

Happy agency is still available if struggling

Happy with support received

Has been a long route to good support

Have been able to get opportunity to go where I want

Have been given more opportunity with this agency

Have support once a week (work one day/wk)

Helpful if staff could give reference

High level of support due to funding

Identified main barriers with staff

Identified strengths

Identified what I was looking for

Identify strengths and weaknesses on own and by feedback from others

Ignorance about AS

Impressed with model of support

Increasing freedom as support reduces

Informal meeting with support agency

Input was 18-24 months ago

Involved with other employment agency previously

Job at support agency would be good

Key support individuals

Lack of support would lead to isolation

Lack of support would struggle to cope on own

Learning more in current placement

Less support than used to have

Level of residential care inappropriate

Limited support

Lots of input from support staff

Lots of support from within the company, once permanent work

Lottery funded

Main placement and backup

More ongoing support for first job / first job in a while

More severe AS / ASD need support

More support in different area

More support means more opportunity

Need to go beyond job search

Needs reliability / predictability to access services

Nice that support agency helps

No access to support agency without diagnosis

No confidence building work

No constant support now

No ideas for improving support

No other support needed

No really bad aspects of support
No support for approx 2 months
Non-specific support agency helped understand Job Centre info
Not all placements enjoyable
Not AS specific support
Not discussed future goals with ASD employment support
Not needed support other than first day
Not supported by any other agency previously
Not sure how to improve support
Not sure how to improve support
Not sure how to improve support
Not sure if need support
Not sure if support agency will arrange progression
Not sure what additional support is needed
Not sure where need support
Nothing agency could have done differently
Nothing ASD employment support could do differently
Nothing I would have changed in support
Nothing missed from support package
Occasional support from staff
One main placement, one backup
One to one support from ASD employment support agency
Others attached to support worker
Person did not find me placement, not useful
Person was meant to find me work placement
Positive support from Autism specific service
Practical support
Previous charity support
Previous placement at employing support agency
Previous placement in ASD support agency
Promote independence and support
Proud of involvement with support agency
Prove to staff
Proving that I can do work
Read Support agency handbook
Really happy with support that has been received
Reassurance from support staff
Receive no support currently
Received support
Reduced support is a good thing
Reducing support with time
Reed most positive support
Repeated access of Shaw Trust
Residential support holds me back
Residents not independent to do work
Role play interviews to get you to know what to do
Second placement at support agency
Significant individual personal support
Skills support
Speaking to agency staff
Specialist ASD support agency
Speech therapy support with conversation
Speech therapy useful
Spoke to employment and support advisor
Spoke to support staff about difficulty asking
Staff are reassuring
Staff available quickly
Staff check I'm OK
Staff close if needed
Staff have given opportunities to help

	Staff left me to it after an hour
	Staff may want to contact
	Staff monitor what can and can't do
	Staff prefer I keep mobile on
	Staff present if you need them
	Staff read it back to me
	Staff record I can do it myself
	Staff supporting with job application
	Staff take note
	Staff ticking goals off / progress
	Staff witness
	Standard letters not helpful
	Standard letters to employers not useful
	Start support when people are out of work / lose their job
	Still get support from ASD support agency
	Strengths profiling at ASD work agency
	Support staff feedback
	Support / friends always available to ask
	Support advise admin might be too hard
	Support advise phones might be too hard
	Support agencies (ASD and non-specific) helped understand Job Centre info
	Support agencies address anger, confidence and finance
	Support agencies bound by contracts
	Support agency course combined with placement to develop communication skills
	Support agency helped me find a job
	Support agency rang and described job opportunity
	Support agency specialises in ASD and AS
	Support as advantage
	Support assessing what support and info needed
	Support available from agency around renewing DLA
	Support backs me up
	Support for frustration in situations like this
	Support from agency helps prepare me
	Support from agency on communication skills
	Support from company helps prepare me
	Support gave massive boost in confidence
	Support gave me the confidence
	Support gets me out of isolation
	Support getting ready for seasons
	Support has been alright
	Support has been well paced
	Support has helped me
	Support helpful
	Support helps
	Support if needed
	Support improved communication
	Support improving communication with other AS /ASD
	Support in big groups with lots of staff
	Support in education prepared for work a little bit
	Support is almost perfect
	Support is alright
	Support is learning me into it
	Support is providing me what I want
	Support is very good
	Support looking for a different work placement
	Support needed to work towards full time goal
	Support needs to be an ongoing process
	Support needs to show how it's done
	Support never going to be 100% perfect
	Support people will come and see how I'm doing

	Support person within employer
	Support providing information is better
	Support received has been very good
	Support received has been very positive
	Support received is absolutely right
	Support received over a number of years
	Support reducing over time
	Support reduction related to proving self
	Support should be started sooner
	Support staff accompanied at interview
	Support staff at interview helpful
	Support staff at interview made feel more comfortable
	Support staff check I'm OK
	Support staff check what I'm doing
	Support staff did practice interview
	Support staff leave me to it most of the time
	Support staff supervise
	Support staff trying to get pass
	Support staff visit 2/3 times a day
	Support staff watch what I do
	Support through life if diagnosed as a child
	Support to build work skills
	Support to find work opportunities
	Support to stay on right path
	Support was a positive experience
	Support was good
	Support was good
	Support will be more of the same
	Support with anxiety and gaining confidence
	Support worker did practice scenarios
	Support working out where going wrong
	Support works
	Support would be better if asked about future goals
	Support would be labour intensive and expensive
	Support: Gave advice on anxiety
	Supported along the right path
	Supported and autonomous
	Supported by job staff
	Supported by one staff
	Supported from school to work
	Supported in the main path
	Supported residential living
	Supported to say the right thing
	Supposed to find me work placement
	SW helped finding jobs
	SW trying to find a job
	Took me to ASD employment agency
	Useful having staff support
	Useful to be shown what to do
	Usually 1 to 1, in case needed it
	Variable support
	Went to previous ASD agency, not useful
	Will ask for support when find difficult job
	Will seek advice and support on contacting employers from Shaw Trust
	Wish support could be more proactive
	Would approach agency for advice around opportunities
	Would approach agency for advice first
	Would be good if could ring staff for help
	Would be nice if someone helped the ASD support agency
	Would like support staff close by, if needed

	Would not change past support
	Would not want any other support
	Would recommend support agency to others
	Would seek agency opinion on opportunities
Family support	Boyfriend helps me
	Boyfriend takes me to nightclub
	Close relatives went away
	Dad arranged interview with support agency
	Dad brings me to work / support
	Dad died
	Dad found ASD employment support agency
	Dad is available to support if necessary
	Dad noticed shy
	Dad researched AS resources
	Dad wondered if AS
	Don't eat if Mum away and now money for takeaway
	Family difficulties affected work
	Family difficulties led to reduced hours
	Family help work out what might be good work to do
	Family support to attend work
	Found job through Mum's friend
	Friends
	Friends have been big support
	Go to nightclub with boyfriend
	Hardly see friends because of jobs
	Helped friend by working
	Live at home with Mum
	Live close to Dad
	Live with Mum
	Live with Mum and Stepdad
	Make friends
	Most friends have jobs
	Mother thinking about future
	Mum always been there for me
	Mum always moves stuff
	Mum and aunt considered ASD
	Mum and aunt suggested going for diagnosis
	Mum and boyfriend take me to places
	Mum didn't want me to go to mainstream school
	Mum drives me
	Mum felt retail would be too difficult
	Mum helped a lot through school and college
	Mum helped at agency
	Mum helps me
	Mum instigated seeking diagnosis
	Mum involved with getting Social Worker to help
	Mum is closer than anybody else
	Mum is closest
	Mum makes it hard for me to find things
	Mum researched ASD
	Mum supportive
	Mum takes me to football
	Mum thought mainstream school would be too hard
	Mum throws stuff in a bin bag somewhere
	Mum throws things away, doesn't actually tidy
	Mum's knowledge of me growing up
	Not able to work weekends as see family
	Parental support
	Parents don't listen to me
	See family at weekends

Training	Want more local friends
	All other people in training course struggled
	Art and design course
	Attempted to get training
	Boring training courses
	Computer course not helpful as too basic
	Could only get funding for low level courses
	Could only get support for inferior course despite same funders
	Course links well with work placement
	Courses gave motivation
	Courses specific to the work
	CV support is repetitive across courses
	Didn't like training courses
	difficulty generalising from courses
	Distrust in training courses
	Distrust of training providers, scam
	Doing courses
	Employment programme for group of 3
	Finished training courses early as was too basic, went home
	Frustrations accessing training
	Games development course
	general support and awareness rather than specific courses
	Information from sessions / training providers
	Life skills programmes
	Like a befriending scheme
	Needed course that would challenge me
	Over-skilled for training courses / groups
	Possible training to cope with frustration
	Private training companies don't have to help you out
	Programme / support has been slow at times
	Programme designed for ASD employment to explore feelings about world of work
	Programme gave confidence and getting used to work
	Programme helped confidence in work
	Repetition at training courses demoralises
	Sessions based on communication
	Trained for work
	Training course for computer skills
	Training course not useful
	Training course repetition 'weakens your spirit'
	Training course similar to placement
	Training course was local
	Training courses advertised
	Training courses for illiterate people
	Training courses make you do CV and read the same paper 5 days wk.
	Training courses make you do CVs
	Training courses should not be 5 days a week
	Training courses tested on basic maths
	Training courses too basic
	Training courses x2
	Training offered was not good enough
	Training programme repetition a waste of time
	Training providers
	Vocational courses
	Want choice of courses
	Wanted to do European computer driving licence
	Wanted training
	With criminals, addicts and severe MH patients

Feedback, Appraisal and Targets	100 claims a day as target
	Better to know if not getting a job
	Company likes its targets
	Could fail to meet standards on small number of errors
	Didn't know of targets at first
	Different seasons equals more pressure
	Fair enough if unsuccessful, but they should tell you
	False sense of hope if not informed about job
	Got to wait for review
	Got to wait for review to increase hours
	Had to achieve 95% pass rate every day
	Had to achieve certain level to be taken of probation
	Honest feedback more important than feelings
	I do everything all right, otherwise they tell me
	Keep on working towards goal
	Keep shelves stocked and well presented
	Kept record / reference of answer
	Lack of replies to applications
	Lots of jobs are target driven
	Lots of jobs set time limits
	Lots of other more viable employees
	Meeting with managers
	Minority of employers don't tell you if unsuccessful
	Moving towards goals
	Never heard back re applications
	No deadlines, just never-ending work
	Performance below targets
	Respect honest feedback
	Review / appraisal
	Review after Christmas
	Review delayed due to Christmas
	Review every 3 months
	Set yourself a goal
	Set yourself small steps
	Setting self targets
	Some days focus on accuracy rather than targets
	Some days focus on numbers so accuracy dropped
	Sometimes good making mistakes so you can put it right
	Standards combined with targets was difficulty combined with targets was difficulty
	Target your goal
	Targeted
	Targets and objectives to hit
	Targets apparent as progresses in the job
	Targets did not help
	Targets difficult to meet
	Targets; walk far and fast
	Time limits not always practical
	Told if don't do job well
	Waiting for application responses
	Want feedback so can adjust
	Want more hours following future reviews
	Work visits to see how I'm doing
Supportive / Positive Colleagues	Beneficial colleagues aware of diagnosis
	Can ask staff for support when necessary
	Colleagues helped me get job done well
	Colleagues helped take pressure off
	Colleagues knew I could do job
	Colleagues supported me to meet targets / objectives
	Feel supported by support staff
	Feel understand AS

	Get on well with staff
	Get on well with team managers
	Have to find colleague when customers ask Q
	I helped colleagues
	Information from staff member
	Met good people
	OK that ask colleagues for support
	Other people help
	Others explained how job is done / how things work
	Team work
What's Needed	Advertise to employers to give ASD a chance for work
	AS helps reduce suspicion
	Attitude change in other workers
	Attitude change in other workers needed
	Continuity important
	Employer needs financial compensation
	Employer still needs experience of AS
	Employer support for things being done fully and right, rather than targets
	Employers could focus on accuracy
	Employers not to judge by diagnosis
	Employers should judge by personalities
	Explain AS
	Finding employer with AS experience is key
	Good for employers understand differences for technical jobs
	Haven't got pass as only part-time
	If uncomfortable with promotion would want option to go back
	Improving understanding of AS helps marginally
	Increasing staff awareness
	May need a couple of hours weekly debrief
	New placements start few hours and build up
	Prefer and respect honesty
	Progress takes planning and opportunity
	Promote honesty and work ethic to employers
	Significant incentives for employer
	Unsure where to go if struggling
	Wage reduction initially
	Wage subsidy needed
	Want advice on right / wrong thing to do
	Warning issues can happen

Excerpt 3. Transitional themes
Sample transitional themes relating to transition support are provided below. These relate closely to the thematic categories that formed the original submission of this study. Following academic feedback and further reflection, the researcher became aware that the level of analysis at this point focuses too heavily on the semantic grouping of codes, largely as a result of the researcher's efforts to remain data driven and close to the semantic information provided by the participants (see Critical reflection, section 8.2.).

Financial Support	Applying for Incapacity and DLA, had to attend medical
	ASD employment support did not get involved in finance / benefits
	Benefit system confusing
	Benefits as life saver
	Benefits do not cover cost of driving
	Benefits removed
	Better assessment for better benefits decision making
	Clearer advice, rules and regulations on payments
	Clearer rules on income support, housing, council tax, DLA and incapacity benefits
	Didn't know was signing on
	Difficult if social services support removed straight away
	Financially better off
	Had to contribute to personal budget
	Higher benefit levels for people with permanent conditions like ASD
	Hope for change in the benefits system
	Jobseekers
	Lower rate DLA
	Money provides opportunity / choice
	More severe ASD deserve higher level payments
	Need better understanding of personal budgets
	Need for financial support
	New level of payment structure
	No benefit at all
	Not eligible for benefits
	On Job Seekers
	Problems when ESA introduced
	Receive all entitled benefits
	Receive DLA
	Receive income support
	Still get benefits with wage
	Still got to sign on
	Successful appeal, benefits reinstated
	Temporary disability report to DWP regularly to enforce
	Trying to figure out personal budget
	Trying to get the right benefits
	Unsuccessful attempts to get advice on personal budget
	Wrong benefit
Benefit Trap	Affects benefits if work over 16 hours
	Benefits at risk from working
	Benefits stop if 16hours a week or more
	Can only work up to 16 hours
	Clearer info how payment affected by employment
	Constantly changing benefits and rules due to government
	Contracted for 16 hours pw
	Council or job centre would pay wage subsidy
	Desire to use social services budget as wage subsidy
	Employment subsidies
	Employment Support Allowance

	Employment support allowance
	ESA advisor
	Got to get 40 hours a week or nothing
	If too much work, lose benefit
	Job / wage subsidy available
	Job needs to mean financially better off and stability
	Limits/constraints of benefits
	Longer wages subsidy better
	Need clearer rules on how payments affected
	Need wages subsidy
	Not better off through working
	Paid work and benefits work out the same
	Paid work deducted from benefits
	Permitted work scheme
	Present leaders trying to get everybody off incapacity into work
	Subsidy, not wage cut
	Work between 15 and 16 hours
	Worse off if worked
Family Support	Boyfriend helps me
	Close relatives went away
	Dad arranged interview with support agency
	Dad brings me to work / support
	Dad found ASD employment support agency
	Dad is available to support if necessary
	Dad researched AS resources
	Dad wondered if AS
	Family difficulties affected work
	Family difficulties led to reduced hours
	Family help work out what might be good work to do
	Family support to attend work
	Found job through Mum's friend
	Friends have been big support
	Mother thinking about future
	Mum always been there for me
	Mum and aunt suggested going for diagnosis
	Mum and boyfriend take me to places
	Mum felt retail would be too difficult
	Mum helped a lot through school and college
	Mum helped at agency
	Mum helps me
	Mum instigated seeking diagnosis
	Mum involved with getting Social Worker to help
	Mum researched ASD
	Mum thought mainstream school would be too hard
	Parental support
	Parents don't listen to me

Employment Agencies	Agencies meeting process targets
	Agencies playing the system
	Agency available if have difficulty
	Agency believes ASD diagnosis
	ASD employment support always available
	ASD employment support available at request
	ASD employment support big help
	ASD employment support check once a day to check OK
	ASD employment support did not get involved in finance / benefits
	ASD employment support ongoing
	Been through all support agencies over long time
	Benefit info from Job Centre and support agency
	Charities support independence and support
	Contingency if placement not working
	Could improve by having backup placement
	Current support relatively cheap and safe
	Ended up with good support
	Enjoy support received
	Enjoyed work / support agency
	Got support
	Got whatever support needed
	Happy with support received
	Helpful if staff could give reference
	Identify strengths and weaknesses on own and by feedback from others
	Impressed with model of support
	Learning more in current placement
	More support means more opportunity
	Need to go beyond job search
	Nice that support agency helps
	No other support needed
	Non-specific support agency helped understand Job Centre info
	Nothing agency could have done differently
	Nothing ASD employment support could do differently
	Nothing I would have changed in support
	Nothing missed from support package
	One main placement, one backup needed
	Personal contract for employment and social issues
	Personal contract to develop skills and networking
	Personal contract to incorporate my views and job centre's
	Positive support from Autism specific service
	Promote independence and support
	Standard letters not helpful
	Standard letters to employers not useful
	Support agencies bound by contracts
	Support backs me up
	Support from agency on communication skills
	Support gave massive boost in confidence
	Support gave me the confidence
	Support gets me out of isolation
	Support helpful
	Support improved communication
	Support improving communication with other AS /ASD
	Support in big groups with lots of staff
	Support is very good
	Support received has been very good
	Support received has been very positive
	Support received is absolutely right
	Support was good
	Support works
	Supported from school to work
	Wish support could be more proactive

Key Professional Support	1 to 1 help me on placement
	Advocate could approach and contact employers
	Advocate to explain to staff
	Can't send email to GP
	Case worker arranged and oversaw everything
	Caseworker assigned
	Caseworker followed up after I started
	Contract with work advocate
	Found job through SLT rather than ASD employment support agency
	In work advocate as example of good resource
	Key person able to offer incentives to employers
	Key person contacted support agency
	Key person in helping to get me a job
	Key person needs authority and budget
	Key person with significant budget and access to employers
	Key support individuals
	Need access to key person
	No desire to go for therapy
	Psychiatrist first, Psychologist 2 years later
	Psychologist at group
	Psychologist opinion had AS
	Same person every time
	Sent to psychiatrist
	SLT did telephone work and conversation practice
	SLT referred to support agency
	Social worker most important
	Social worker best placed for work support
	Somebody to act as advocate and pave the way
	Speech therapy useful
	Spoke to key person
	Support person within employer
	Told someone at college wanted to get into work
	Want help, someone to identify where going wrong
	Went to neuropsychologist

Groups and Training	All other people in training course struggled
	Anger group in other specialists and support units
	Anger group separate from work
	Art and design course
	AS Women's group as useful to transition / work
	At least group was attempting to do something / influence strategy
	Attended AS women's group
	Attended ASD employment programme
	Boring training courses
	Communication support groups help work
	Computer course not helpful as too basic
	Could be honest in small group
	Could only get funding for low level courses
	Could only get support for inferior course despite same funders
	Course links well with work placement
	Courses gave motivation
	Courses specific to the work
	CV support is repetitive across courses
	Didn't like training courses
	Difficulty accessing courses
	Distrust in training courses
	Employment programme for group of 3
	Frustrations not able to access training
	Games development course
	Gateway to work programme as a group
	Group appeared to be more for ASD than AS
	Group attended was not appropriate
	Group hit lots of points on the head
	Group involved with Autism Strategy
	Group is easy access from train station
	Group leader could relate
	Group leader had been in same boat
	Group more proactive
	Group was helpful
	Group: social activities
	Groups need resources, rooms and funds
	Groups rely on variable funding
	Information from sessions / training providers
	Joined readers group
	Lack of shared interest in the group
	Lack of support would lead to isolation
	Life skills programmes
	Like a befriending scheme
	Limited funding for short courses
	Mainly women in the group
	More like a therapy session
	Most support groups down south
	Need money for courses
	Needed course that would challenge me
	Negative medical model in group
	Nice and Relaxed group
	No guarantee group will run
	No local support groups
	Others from group are decent people
	Over-skilled for training courses / groups
	Pay back money for course once earning
	Positive social model in group
	Pre-selected group of similar people
	Programme / support has been slow at times
	Programme designed for ASD employment to explore feelings about world of work

	Programme gave confidence and getting used to work
	Programme helped confidence in work
	Readers group closed because of library cuts
	Returning to work group
	Self diagnosis as problem in the groups
	Small group better than large, couldn't cope
	Social activities
	Social group run by students during term time
	Stopped attending AS women's group due to work
	Support agencies address anger, confidence and finance
	Support groups should recognise having to sign on
	Support groups tend to be near city centres
	Support with anxiety and gaining confidence
	Support: Gave advice on anxiety
	Training course for computer skills
	Training course not useful
	Training course repetition 'weakens your spirit'
	Training course similar to placement
	Training course was local
	Training courses for illiterate people
	Training courses make you do CV and read the same paper 5 days wk.
	Training courses should not be 5 days a week
	Training courses too basic
	Training offered was not good enough
	Training programme repetition a waste of time
	Tried to get involved with voluntary groups
	Useful as met lots of people with AS
	Vocational courses
	Want short courses
	Wanted to do European computer driving licence
	With criminals, addicts and severe MH patients
	Work placement clashes with group

Excerpt 4. Finalised transition support theme

Subthemes and codes comprising the finalised transition support theme are provided below. Efforts to move away from semantic grouping of the data seen in Excerpt 3 are evident, in response to the academic feedback and reflections following the initial submission of the study. Tensions between the semantic, data driven intentions of the researcher and the influence of more deductive and latent processes are emphasised at this stage. See Critical reflection (section 8.2.) for further discussion.

Transition Support		Notes
Emotional Needs	More like a therapy session Not able to cope Might kick back against bullying Panic attack Pointlessness Terrifying and confusing world Aspergers as possible cause for major mental illness due to isolation Cut-off / isolated Cuts me up knowing not part of working society Humiliated Hopelessness Feel stuck Reassurance from support staff Get nervous 2 days before anything new Worry about difficulty at work Worry if doing work correctly Fed up and pissed off it has taken so long Stuck in a hole Risk of future depressive relapse Time pressures at work might have impacted relapse Personal issues impacting on MH Availability of training as frustration Unfairness / feel victimised Disability or Mental Health impacting employment Family difficulties affected work Family difficulties led to reduced hours Would be better if agency could build confidence Anger group in other specialists and support units Anger group separate from work Programme gave confidence and getting used to work Anger support around bullying, social interactions, physical and verbal aggression Support with anxiety and gaining confidence Anxiety management partially addressed by charities / support agencies Programme designed for ASD employment to explore feelings about world of work Support agencies address anger, confidence and finance Lack of support would lead to isolation Support for frustration in situations like this Manage to control anger at work Anxiety when not familiar Anxious when starting placement	Therapeutic groups Anxiety / Anger / Mood Personal issues
Practical Support	More support means more opportunity Support helpful Support was good Nothing I would have changed in support Happy with support received Ended up with good support Enjoy support received Nothing missed from support package	Positive view of support provision

	Would recommend support agency to others	
	No other support needed	
	Support received has been very positive	
	ASD employment support big help	
	Nothing ASD employment support could do differently	
	Would not want any other support	
	Nice that support agency helps	
	Would not change past support	
	Support received is absolutely right	
	Nothing agency could have done differently	
	Support is very good	
	Support received has been very good	
	Enjoyed work / support agency	
	Support works	
	Positive support from Autism specific service	
Practical Support – Finding a Job	Mum and boyfriend take me to places	Job search & CV Confusion / Advice / Direction Starts young / Links Financial
	Found job through Mum's friend	
	Job Centre sending for job searches was useful	
	Come to ASD support agency to do job search	
	Job search on the computer	
	Receive DLA	
	Receive income support	
	Jobseekers	
	Person did not find me placement, not useful	
	Person was meant to find me work placement	
	ASD employment support agency needed to communicate	
	ASD employment support agency needed to help with job search	
	Supposed to find me work placement	
	ASD employment support agency did not communicate	
	Agency did not contact me	
	Was meant to do job searches but didn't	
	One to one support at college	
	Told someone at college wanted to get into work	
	College contact put in touch with ASD employment support	
	Font too small on CV	
	Font smaller so could fit text on a few pages	
	People have complained CV is hard to read	
	Wanted lots of information on CV without having a dozen pages	
	Help with CVs on courses not useful	
	Needs reliability / predictability to access services	
	Need people to arrange appointments for me	
	Need Social Services to chase me up	
	Training courses make you do CV and read the same paper 5 days wk.	
	CV support is repetitive across courses	
	Paper always has same jobs	
	Mother thinking about future	
	Mum and aunt suggested going for diagnosis	
	Mum instigated seeking diagnosis	
	Mum researched ASD	
	Support should be started sooner	
	School not experienced in those difficulties	
	School slow on support	
	Helpful if staff could give reference	
	Have been able to get opportunity to go where I want	
	Supported from school to work	
	Searching for a job	
	Help job searching	
	Staff supporting with job application	
	Took me to ASD employment agency	
	Creating CV for first time	

Second CV was much better First CV was bad Feedback on CV Unsure what CV should look like SW helped finding jobs Got reference from work placement Social worker found work SW helped finding jobs SW trying to find a job Encouragement to find more work Encouragement was good Benefits as life saver Key person in helping to get me a job Social worker most important Social worker best placed for work support Key support individuals Spoke to key person Key support individuals Need one person at Job Centre Difficulty getting experience Job search scheme Limited job searching Tried to pursue work Applying for work Hard to find a job at first Mum helped a lot through school and college Support agency helped me find a job Agency helps find job Agency has found a number of jobs School referred to support agency School and agency connected Dad arranged interview with support agency Dad found ASD employment support agency Dad researched AS resources Dad wondered if AS Informal meeting with support agency Lower rate DLA Try to update CV 1 to 1 support at college 1 to 1 support at school Receive all entitled benefits Mum involved with getting Social Worker to help Family help work out what might be good work to do College support would help break things down ASD employment support agency helped look for work ASD support agency always phone people to get work ASD employment support help with interview ASD employment support help with CV ASD employment support helped look for work Job Centre have machines to help look for jobs Job Centre should ask if we need help On Job Seekers Would like support on how to do CV College referred to ASD employment support agency Need access to key person Contract with work advocate Somebody to act as advocate and pave the way Key person with significant budget and access to employers Key person able to offer incentives to employers Key person needs authority and budget	

	Same person every time	
	In work advocate as example of good resource	
	Advocate could approach and contact employers	
	Advocate to explain to staff	
	Always different person at job centre	
	Lack of info on CV	
	Society needs explanation for age and lack of job	
	People will think worst due to lack of history	
	False claim of communication skills and team player	
	Team player on every job description	
	Send letters out	
	Plan to send letters to employers being honest about AS	
	Letters include, team player, good communicator and flexible, but i'm not	
	Develop networking is important	
	Getting the job in the first place is the barrier	
	Standard letters to employers not useful	
	More than job search	
	Didn't need job search	
	Job search support is pointless	
Practical Support- Starting Work	Arranged working interview, rather than normal interview	Interviews Placements Training / Courses Case worker / Advocate
	Arranging interviews most useful	
	Avoiding normal interviews most useful	
	Support worker did practice scenarios	
	ASD employment agency did work on interview skills/technique	
	ASD employment agency arranged some normal interviews	
	Not great deal of interview practice	
	Putting myself across at interviews a difficulty	
	Arranging interviews most useful	
	Avoiding normal interviews most useful	
	Working interview involved training then job trial	
	Working interview preferable	
	Interview support most useful	
	Practice interviews were helpful	
	Practice interviews may go out window for real thing	
	Support staff did practice interview	
	Support staff at interview made feel more comfortable	
	Support staff at interview helpful	
	Support staff accompanied at interview	
	Interview as biggest barrier	
	Interview just a few questions	
	Interview; just wanted to meet me	
	Interviewed about type of work wanted	
	Nervous about interview before	
	Mumbled in interview	
	Practice interview hour before real interview	
	Practice interview was useful	
	Practice interview with support staff	
	Had interview practice, useful in confidence	
	Basically got job before interview	
	Didn't know where to go for work opportunities	
	Six month trial	
	Interview at Shaw Trust not what I needed	
	Need to go beyond job search	
	Wish support could be more proactive	
	Standard letters not helpful	
	Support will be more of the same	
	Not AS specific support	
	Limited support	
	Agency got placement at blind charity	
	ASD agency found me work placement	

	Found placement through agency	
	Finding work placement is best part of support	
	Mock interviews were useful	
	Telephone and conversation practice was useful	
	Applied for 3 retail jobs	
	first successful application	
	Applied for jobs	
	Would find it difficult to work out what to apply for alone	
	Interviews as hard	
	Interview role play was useful	
	Interviews for all previous applications	
	Didn't tell you it was a group interview	
	Had four interviews previously	
	Don't like interviews	
	Not successful at 3 interviews	
	Had to figure out group task	
	Had group interview of 12	
	No interview for current job	
	Had to team work at group interview	
	Should have told me it was a group interview	
	Talking to people as barrier to interviews	
	Group interview was difficult	
	Confidence as barrier to interviews	
	Would like more practice interacting with people	
	Role play interviews to get you to know what to do	
	Job Centre not helpful at all	
	Programme / support has been slow at times	
	Communication difficulty in interview	
	Develop work-focussed assessments	
	Had to meet with placement provider	
	Support going to interviews	
	Task focussed assessment	
	Nervous in interview	
	Course links well with work placement	
	Courses specific to the work	
	Contingency if placement not working	
	Work placement was most useful	
	Could improve by having backup placement	
	Employment programme for group of 3	
	Life skills programmes	
	Communication support groups help work	
	Attended ASD employment programme	
	Support from agency on communication skills	
	Communication support groups help work	
	1 to 1 skills support on placement	
	1 to 1 help me on placement	
	Applied for a few jobs	
	Applied for bar work	
	Apply for as many jobs as I can	
	Applied for retail jobs	
	Said to key person wanted job	
	Hardest thing is finding a job	
	Persistence applying	
	Determination important	
	Gone around asking for jobs	
	Not anxious about working or applying	
	Applied for computer technician job	
	Applied to join army	
	Applying for jobs and not getting response a difficulty	
	Not applied for apprenticeships, too old	

	Placements useful part of training programmes		
	Interview process as barrier		
	Mumbling in interview		
	Interview in small room		
	Didn't feel lacked confidence in interview despite this being perceived by interviewers		
	Never having met interviewers made it stranger		
	5 women interviewing me in a cramped room was strange		
	Mumbling in interview		
	Gateway to work programme as a group		
	Training course for computer skills		
Practical Support - Developing in Work	ASD employment support help you put things right	Gradual increase
	ASD employment support help break things down	Courses
	Family support to attend work	Build confidence
	Break things down helps learn better	Employer flexibility
	Feedback if do it wrong, so can do it right	
	Feel comfortable interacting with employer team managers	
	Team managers within employer for support	
	Employer team managers are helpful	
	Support person within employer	
	Want help, someone to identify where going wrong	
	Pleased to have learned through transition	
	Feel good about working autonomously	
	Better at talking to people following transition	
	Good at team work / working with others	
	Each week at work has built confidence	
	More confident following transition	
	Learnt team work at college	
	Useful to be shown what to do	
	Always support staff in the office when working	
	Support staff check what I'm doing	
	Dad brings me to work / support	
	Dad is available to support if necessary	
	No confidence building work	
	Work is helping to build confidence	
	Fine working with people now	
	Enjoy the fact I'm working the best	
	Just enjoy I'm doing something	
	Feels good to be working	
	Can hold conversations on topics which are personally interesting	
	Guidance on how to deal with issues / people	
	Learnt to mimic behaviour	
	Practice being around people	
	Support gets me out of isolation	
	Work will mediate difficulties	
	Imposes routine on me	
	Job title means status and dignity	
	Group: With criminals, addicts and severe MH patients	
	Lack of shared interest in the group	
	Support groups should recognise having to sign on	
	Mainly women in the group	
	Not capable of full-time straight away	
	Better over time	
	Better at social interaction than use to be	
	People with AS experiment to be part of a community	
	Talking on the phone has brought me out of myself	
	Finding it easier to be talkative in current job	
	Socialisation not an issue in current job	
	Social skills lead to confidence	
	Getting on fine in this job and the people in it	
	Case worker arranged and oversaw everything	

	Caseworker followed up after I started	
	Caseworker assigned	
	Employer flexible with shift patterns	
	Company were very understanding	
	Always have opportunity to say no to shifts	
	Best job I've ever had	
	Enjoy call centre job	
	Improved since left education	
	Got voice and sense of humour back after school	
	Company available if have difficulty	
	Lots of support from within the company, once permanent work	
	Become more social	
	Job helps communicate with colleagues	
	Since being with people, out of own world	
	Work helped with social skills	
	Enjoy current job	
	Enjoyment	
	Got motivated and started enjoying work	
	Progress / regaining mental health	
	Courses gave motivation	
	Vocational courses	
	Needed course that would challenge me	
	Want short courses	
	Difficulty accessing courses	
	Training courses too basic	
	Training offered was not good enough	
	Work placement clashes with group	
	Learning more in current placement	
	Stopped attending AS women's group due to work	
	Did an IT course at college useful	
	Working has helped improve speed of work	
	Can work faster now	
	Social aspect of being in a team has helped me	
	Confidence to work faster	
	Confidence has improved	
	Building work hours would build confidence	
	Enjoy job	
	Enjoy volunteering at day centre	
	Enjoy working less hours	
	Boring training courses	
	Over-skilled for training courses / groups	
	Distrust in training courses	
	Didn't like training courses	
	Computer course not helpful as too basic	
	All other people in training course struggled	
	Training courses should not be 5 days a week	
	Training programme repetition a waste of time	
	Job Centre sends you on training courses	
	Training course not useful	
	Training course repetition 'weakens your spirit'	
	Training course similar to placement	
	Training courses for illiterate people	
	Placement increased work focussed behaviour	
	Working on improving communication whilst on placement	
	Learnt to be more respectful and positive with others	
	Enjoy work	
	Support improved communication	
	Support improving communication with other AS /ASD	
	Support gave me the confidence	
	Charities support independence and support	

	Support agency course combined with placement to develop communication skills Developed politeness Developed patience Work would build confidence Really good fun Enjoying work Support to build work skills Support gave massive boost in confidence Employer will contact when post free Support needs to show how it's done	
Practical Support – Moving Towards Autonomy	Difficult if social services support removed straight away Job needs to mean financially better off and stability Financially better off Still get benefits with wage Continuity important Money provides opportunity / choice Want any job that pays the bills Good that support is reducing Hope for more independence in future Want to be more independent Current support helps move towards independence Increasing freedom as support reduces Support reducing over time Staff present if you need them Want part time work Support people will come and see how I'm doing Working towards longer hours and paid Would ideally work part time, rather than full time Part time voluntary work More ongoing support for first job / first job in a while Receive no support currently Support needs to be an ongoing process Need less services now Rely on income from work Being paid for work Still get support from ASD support agency No support for approx 2 months Happy agency is still available if struggling Support received over a number of years Reduced support is a good thing Less support than used to have Would seek agency opinion on opportunities Would approach agency for advice around opportunities Support from agency helps prepare me Agency available if have difficulty Work hours have increased over support Got permanent job after 2 years Need for financial support Paid/voluntary split Wage/benefit balance Paid / voluntary split Gaining a living Doing well = reduction in support Reducing support with time Placement days were good Part time Lack of learning at school 3 hours work increased to 7 hours No constant support now ASD employment support ongoing	Financial / wage subsidy Ongoing / diminishing / continuity Enjoyment / job satisfaction voluntary work

	Constant support when started	
	Don't need support now, work autonomously	
	ASD employment support there if I get stuck	
	ASD employment support always available	
	ASD employment support check once a day to check OK	
	ASD employment support available at request	
	Good that ASD employment support always available	
	Help at college if you ever needed it	
	Paid work is better	
	ASD employment support always been there	
	Want to be paid for current job	
	Process of building up hours	
	Work hours reduced because it's a new placement	
	Started off working 3 hours	
	Built up to full day working	
	Occasional support from staff	
	Support needed to work towards full time goal	
	Have support once a week (work one day/wk)	
	New placements start few hours and build up	
	Work for employment unit at college useful	
	College was really helpful	
	Paid / voluntary split	
	Not ready for more work at the moment	
	Not needed support other than first day	
	Support staff leave me to it most of the time	
	Support has been well paced	
	Staff left me to it after an hour	
	Work visits to see how I'm doing	
	Part time work better	
	Didn't go back as low paid	
Clear Guidance and Honest Feedback	Respect honest feedback	Feedback / Different sources
	Support assessing what support and info needed	Advice
	Staff ticking goals off / progress	Identify strengths
	Need feedback if work not good enough	
	Honest feedback more important than feelings	
	Waiting for application responses	
	Lack of replies to applications	
	Staff record I can do it myself	
	Staff monitor what can and can't do	
	Would approach agency for advice first	
	Comfortable to approach agency for advice	
	Didn't know of targets at first	
	Targets and objectives to hit	
	Got to wait for review to increase hours	
	Review every 3 months	
	Support staff watch what I do	
	Support staff supervise	
	Support staff feedback	
	Job Centre should give more advice	
	Mum felt retail would be too difficult	
	Mum thought mainstream school would be too hard	
	Support working out where going wrong	
	Never heard back re applications	
	I do everything all right, otherwise they tell me	
	Feedback is given in nice supportive way	
	Support advise phones might be too hard	
	Support advise admin might be too hard	
	Support would be better if asked about future goals	
	ASD employment support feedback if doing things wrong	
	Identified strengths	

	Strengths profiling at ASD work agency	
	Identified what I was looking for	
	Targets did not help	
	Could fail to meet standards on small number of errors	
	Had to achieve certain level to be taken of probation	
	No deadlines, just never-ending work	
	Performance below targets	
	Some days focus on accuracy rather than targets	
	Some days focus on numbers so accuracy dropped	
	Standards combined with targets was difficulty	
	Appraised as 'doing the job well but very quiet'	
	Need to be more flexible or realistic about targets	
	Strengths profiling at ASD work agency	
	Employers need to focus on strengths	
	Time limits not always practical	
	Targets difficult to meet	
	Want feedback so can adjust	
	Minority of employers don't tell you if unsuccessful	
	False sense of hope if not informed about job	
	Fair enough if unsuccessful, but they should tell you	
	Better to know if not getting a job	
	Need feedback from applications so know what to adjust	
	Kept record / reference of answer	
	Setting self targets	
	Information from staff member	
	Identified main barriers with staff	
	Identify strengths and weaknesses on own and by feedback from others	
	Support agencies (ASD and non-specific) helped understand Job Centre info	
	Job Centre provided info, lacked clarity	
	Unsuccessful attempts to get advice on personal budget	
	Want advice on right / wrong thing to do	
	Non-specific support agency helped understand Job Centre info	
	Benefit info from Job Centre and support agency	
	Support: Gave advice on anxiety	
	Job Centre and non-specific agency helped understand advice	
	Support available from agency around renewing DLA	
	Information from sessions / training providers	
	Support agency rang and described job opportunity	
Social Integration	Tried to get involved with voluntary groups	Positive interactions
	Met good people	Acceptance
	Group leader could relate	Met other people with ASC
	Group leader had been in same boat	
	Colleagues helped me get job done well	
	Colleagues helped take pressure off	
	Colleagues supported me to meet targets / objectives	
	Colleagues knew I could do job	
	Others explained how job is done / how things work	
	I helped colleagues	
	Team work	
	Was around other ASD people at school	
	Mum always been there for me	
	OK that ask colleagues for support	
	Have to find colleague when customers ask Q	
	Attended AS women's group	
	AS Women's group as useful to transition / work	
	Useful as met lots of people with AS	
	Get other people to answer the phone	
	Get on well with team managers	
	All my friends were at college	
	Friends have been big support	

	Can talk to support / friends Support / friends always available to ask ASD employment support accepting Could be honest in small group Small group better than large, couldn't cope Others from group are decent people Social activities Like a befriending scheme Social group run by students during term time Joined readers group Returning to work group Pre-selected group of similar people Trust in employer, due to their investment in you	

Appendix 10. Excerpt from reflective log

Coding:

How much meaning? Need to focus on the semantic content of the transcripts to adhere to the methodology but have been exposed to my perceptions of the participant's meaning from the interviews. This is also potentially informed by my knowledge of the literature base, which risks bringing in deductive ideas. This is to some extent inevitable, but does not necessarily constitute a weakness in the study. Inductive – deductive and semantic – latent could be considered spectrums (Braun & Clarke, 2006). Note to self to remain more focused on semantic content and inductive perspective.

Felt like I was re-typing the transcripts when coding, probably due to semantic nature of the analysis.

Am I representing the participant's views and beliefs accurately? Reminder to stay close to the data.

How much is my experience of the other interviews clouding my choice of codes? Is it wrong if it is influencing my choice of codes? My emersion in the data will inevitably do this. However, how much is this influenced by other factors such as, my background reading and literature searching, conversations with professionals whilst recruiting and professionally, and other influences on my beliefs and attitudes to supporting people to transition to work.

Do participants who talk for longer and provide more data get a bigger proportion of representation in the analysis and write up? How do I control for this? Should I control for this? How do I represent saliency (Buetow, 2010) and frequency fairly?

Research tutors coding style slightly different to mine. Discussed with peer using the same methodology on a different study who had experienced the same. Uncertain of influence of myself on the delineation of codes / themes. When does a code become a theme? How much 'meaning' should be in a code? How objective and true to the participant's meaning am I being? Hence, benefits of checking back use of quotes with the participants and peer review with research tutor.

Appendix 11. Recruitment advert for National Autistic Society website

Autism and Transition to Work: A Thematic Analysis of Service User Experiences

A Trainee Clinical Psychologist at the University of Lincoln is conducting research into the experiences of people with autism and Asperger's Syndrome as they are supported into work. Current research suggests that people with autism (including Asperger's) often struggle to find jobs, especially when they have not been working before. Leaving education, like school or college, and moving into a work environment is called 'transition to work'. Work can either be paid or voluntary, as well as supported or unsupported. Transition to work can be a very stressful time and people with autism may benefit from extra support to help them find a job and keep it. Lots of people have tried to come up with ideas about how best to help people with autism transition to work. Most of these people have been professionals who work with people with autism and not people with autism themselves. We want to find out from people with autism what it is like to 'transition to work'. We hope that by hearing the views and experiences of people with autism we can help to work out how to support people better in their transition to work. We want to interview up to 10 adults with a diagnosis of any autism spectrum disorder, including autism, Asperger's Syndrome and pervasive developmental disorder, who have experienced a transition into a working environment. This does not need to have been recent, but you do need to have a good memory of what it was like for you. If you do decide that you do wish to participate, the researcher will arrange to interview you at a time and place convenient to you; therefore, it will not be possible to refund travel expenses. Unfortunately, we are only able to interview participants within the Yorkshire, Derbyshire, Nottinghamshire, Lincolnshire and Greater Manchester areas. Interviews are likely to last 30 to 90 minutes and you will receive a £10 high street voucher in recognition the time commitment involved in your participation. If you would like to participate in this research project, or require any further information please contact Tom Brockwell on ▓▓▓▓▓▓▓▓ or ▓▓▓▓▓▓▓▓▓▓▓▓▓▓▓▓▓▓▓. This research is part of a Doctorate in Clinical Psychology at the University of Lincoln and has been approved by the university ethics board. Many thanks for taking the time to read this.

Appendix 12. Sage manuscript submission guidelines

Available from: http://www.uk.sagepub.com/msg/aut.htm (accessed 20 February 2012).