

# Transition to work: Perspectives from the autism spectrum

Autism

1–14

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Darren Hedley<sup>1</sup>, Ru Cai<sup>1,2</sup>, Mirko Uljarevic<sup>1,2</sup>, Mathilda Wilmot<sup>1</sup>, Jennifer R Spoor<sup>3</sup>, Amanda Richdale<sup>1,2</sup> and Cheryl Dissanayake<sup>1</sup>

## Abstract

To improve employment outcomes for adults with autism spectrum disorder, it is necessary to identify factors associated with successful transition to work from the perspectives of the individual and from those who work with or support them. This study involved focus groups with adults with autism spectrum disorder ( $n=9$ ) participating in a 3-year employment and training programme, as well as focus groups with family members ( $n=6$ ), support staff ( $n=7$ ) and co-workers ( $n=6$ ). The aim was to gain better understanding of the experience of transition to work, barriers and also the factors that promote workplace success. Main themes included factors that facilitated success at work (*Enablers*), barriers to success (*Challenges*) and programme outcomes (*Outcomes*). Organisation support, advice from co-workers, supportive leadership, allowance of environmental modifications and presence of a consultant were identified as enablers that most facilitated success at work. Challenges included task-related difficulties, individual factors, social difficulties and distractibility, not managing work-related stress, and being perceived to be too frank. Outcomes were rated as positive and encompassed work-related outcomes, as well as outcomes related to sense of purpose, achieving personal independence and improvements in social relationships, both with work colleagues and within families.

## Keywords

adults, autism spectrum disorder, barriers, enablers, outcome, qualitative research, supported employment, vocational/labour force participation, work

Adults with autism spectrum disorder (ASD) face significant challenges entering the workforce and maintaining meaningful employment, which is reflected in high rates of both unemployment and underemployment (Baldwin et al., 2014; Howlin et al., 2004; Roux et al., 2013; Shattuck et al., 2012a; Taylor et al., 2015). Increasing work participation among individuals with ASD and other disabilities is likely to have significant and broad economic benefits (Buescher et al., 2014; Kemper et al., 2009; Knapp et al., 2009). Moreover, employment can positively impact the health and well-being of the individual (Chen et al., 2015; Creed and Macintyre, 2001; Feather and O'Brien, 1986). Understanding the factors that inhibit and facilitate successful transition and integration into work from the perspectives of diverse stakeholders has significant potential for influencing current practices associated with the employment of individuals with ASD, as well as the development and implementation of appropriate and successful employment interventions (for a comprehensive review of the literature on employment programmes in ASD, see Hedley et al., 2016).

Studies on the economic impact of ASD in the United Kingdom and the United States have estimated that the national cost for adults with ASD, excluding benefits paid, is between Great Britain Pound (GBP) £25–31 billion and United States dollar (USD) \$175–196 billion, respectively (Buescher et al., 2014; Knapp et al., 2009).<sup>1</sup> Moreover, Knapp and colleagues identified that 36% of costs were attributable to lost employment for both the individuals with ASD and their family members. In Australia, a report commissioned by the Network on Disability suggested that a one-third reduction in the difference between employment rates for people with and without disabilities

<sup>1</sup>Olga Tennison Autism Research Centre, La Trobe University, Australia

<sup>2</sup>Cooperative Research Centre for Living with Autism (Autism CRC), Australia

<sup>3</sup>Department of Management and Marketing, La Trobe University, Australia

## Corresponding author:

Darren Hedley, Olga Tennison Autism Research Centre, School of Psychology and Public Health, La Trobe University, Melbourne, VIC 3086, Australia.

Email: D.Hedley@latrobe.edu.au

would result in Australian dollar (AUD) \$43 billion increase and long-term rise of 0.85% in Australia's GDP (Deloitte Access Economics, 2011). When assessing the potential benefits of increasing the education and employment access of people with disabilities in Ontario, Canada, it was predicted that, with only a 2% increase in the employment rate, the province would see a Canadian dollar (CAD) \$151 million decrease in support payments made, and a total combined benefit to Ontario of CAD \$510 million (Kemper et al., 2009).

Employment is not only important from an economic standpoint, but it is also a vital part of an individual's well-being. Independence, self-esteem, community engagement and social status are all related to an individual's capacity to work, and employment has a positive effect on physical and mental health (Chen et al., 2015; Creed and Macintyre, 2001; Feather and O'Brien, 1986). The desire to be employed, and the view that it is an important goal, is common in people with ASD (Chen et al., 2015). Furthermore, those who are employed are more likely to experience a better quality of life and improved cognitive and mental health outcomes than those who are not employed (Chiang et al., 2013; Hendricks, 2010; Mavranzouli et al., 2014). However, successfully navigating traditional job interviews, complex work environments, including often challenging social dynamics, varied communication requirements and need for flexibility, means that not only finding suitable employment is difficult for adults with ASD, but maintaining employment also presents a major problem if appropriate supports are not available (Baldwin et al., 2014; Richards, 2012; Roux et al., 2015; Shattuck et al., 2012a).

Despite the economic and health benefits that come from successful engagement in work, the employment rate for people with ASD in developed countries is consistently reported to be lower than that for any other disability group (Chen et al., 2015; Shattuck et al., 2012a). The Australian Bureau of Statistics (ABS, 2014) reported a workforce participation rate of only 42% for individuals with ASD, a rate much lower than for people with other disabilities (53%). Moreover, those who are employed often find it difficult to adjust to new work settings are more likely to change jobs and earn less than their peers with equivalent qualifications and experience (Baldwin et al., 2014; Barnhill, 2007; Hendricks, 2010; Roux et al., 2015).

While the challenges and barriers to gaining and maintaining successful employment faced by individuals with ASD are well described (Hendricks, 2010; Müller et al., 2003; Scott et al., 2015), there is limited research on their work experience, or identification of the factors that contribute to successful transition to employment. Moreover, there is growing understanding that the experiences of working adults with ASD should be included as part of practice-based evidence to support policy and programmes that are aimed at increasing rates of employment (Johnson

and Joshi, 2016; Nicholas et al., 2016; Shattuck et al., 2012b). There is, therefore, a definite need to understand the issues around employment from the perspective of the individuals involved and those who work with or support them.

The aim in this study was to document the experiences of individuals with ASD who had been selected for a 3-year supported employment and training programme in Australia as they transitioned to work, along with the factors that promoted, and/or obstructed, their success in the workplace. We conducted a series of focus groups with these individuals, as well as their family members, support staff and co-workers. Including individuals who had different relationships with the trainees, both in and outside of the work environment, provided multiple perspectives concerning the transition process.

## Methods

### *Participants*

In all, 28 individuals participated in the focus groups. In total, 11 adult trainees with ASD who had been engaged in the employment programme for a period of 7 months were invited to participate; one individual declined, and one individual was on leave at the time the groups were run, resulting in nine participating trainees. Trainees were required to provide evidence of their ASD diagnosis (e.g. diagnostic report, letter from a general practitioner) in order to be included in the programme. Seven support staff, six co-workers and six family members of trainees (five parents and one spouse) also participated.

### *Employment programme*

Trainees worked as software test analysts in a supported work environment within the Australian Government Department of Human Services (DHS). The 'Dandelion Program' is a joint initiative by DHS and the information technology company, Hewlett Packard Enterprise (HPE), aimed at providing employment opportunities to individuals with ASD. Recruitment was managed by Danish company 'Specialisterne' (<http://specialisternefoundation.com>) and was competitive. The programme was advertised through local ASD service providers and attracted 63 applicants. Of these, 24 applicants were selected to attend a 1-day workshop where they were provided information about the programme, were observed while participating in group activities, and were interviewed. In all, 14 applicants were subsequently invited to attend the 4-week assessment and training programme, following which formal job offers were made to 12 candidates. In total, 11 individuals accepted offers and were subsequently employed by HPE to provide software testing services within DHS. Trainees entered the programme at HPE

graduate entry level and salary and were employed at an equivalent level and salary to peers without ASD working in similar roles.

Trainees were divided into three teams and worked in a standard office building alongside DHS employees (co-workers). Teams worked on different projects (e.g. mobile technology, customer interfaces). Co-workers were employed by DHS as software test analysts and were not part of the programme. However, they did interact with trainees and often worked together on the same projects. Support staff included experienced test analysts, and one 'consultant' who had substantial experience working with people with ASD. She provided individual counselling, mediation, advocacy and developed strategies to assist trainees in their work.

### Procedure

The study was approved by La Trobe University Human Ethics Committee. Participants were identified by the worksite; trainees provided contact details for family members. Participation was voluntary and informed consent was obtained along with completion of a questionnaire which included basic demographic information and employment history. Additionally, trainees completed the Autism Spectrum Quotient (AQ; Baron-Cohen et al., 2001) and the Waisman Activities of Daily Living scale (W-ADL; Maenner et al., 2013). The AQ is a 50-item, self-report questionnaire that assesses behaviours or traits thought to be associated with ASD. Items are coded as 0 or 1 based on responses using a 4-point Likert scale. Scores  $\geq 26$  are associated with a diagnosis of ASD (Woodbury-Smith et al., 2005). The W-ADL is a 17-item self- or parent-completed scale designed to assess ADL in individuals with developmental disability. Items are rated as 0 ('independent or do on own'), 1 ('do with help') or 2 ('do not do at all') and are summed to provide a total score (range: 0–34), with higher scores indicative of greater independence.

Employment programmes and interventions targeting individuals with ASD were systematically reviewed (Hedley et al., 2016) in order to identify a list of themes that would be suitable for the focus groups. These themes were used to develop a structured guide (see Appendix 1) and included barriers and enablers to success at work; experiences, expectations and apprehensions about the programme; relationships; activities outside of work; past work experiences; and experience/knowledge of ASD. A semi-structured approach to conducting focus groups has been recommended as the most appropriate approach for individuals with ASD who may have specific needs and sensitivities, and to avoid the development of 'off topic' discussions (Nicholas et al., 2016). Eight focus groups lasting approximately 90 min each were conducted by the first author (trainee:  $n = 3$  groups; co-worker:  $n = 2$  groups;

support staff:  $n = 1$  group; family:  $n = 2$  groups). Groups were held at the worksite, or in the case of one family (two parents), at the place of residence. To allow adequate time to consider each issue and to encourage individual contributions to the questions, questions were asked one at a time and trainee group size was constrained ( $n = 3$  members per group).

At the start of each group, participants were provided with information about the study and were informed that they could withdraw at any time. Guidelines for the ethical conduct of focus groups (Morgan, 1998) were adhered to so that participants understood their rights and responsibilities, and that their right to confidentiality and privacy was respected. This was achieved by following a standard protocol where issues of confidentiality and what was expected were read and discussed prior to beginning each group (please refer to Krueger, 1998; Morgan, 1998). Specifically, to maintain confidentiality and encourage open discussion, participants were asked not to repeat information discussed in the group. Participants were also informed that there were no 'right' or 'wrong' answers, that both sides (positive and negative) of an issue were equally important and should be discussed, and that women's and men's ideas would be equally represented and respected. Sessions were recorded on a Dell Latitude laptop using the Audacity® software program. Participants were informed that recordings would be transcribed, anonymised by removing names and other potentially identifying information, and that the original recordings would then be destroyed.

### Data analysis

To ensure comprehensive data reporting, we adhered to consolidated criteria for reporting qualitative research (COREQ) guidelines (Tong et al., 2007). We adopted an inductive approach to content analysis which is effective in addressing specific objectives and questions (Raspa et al., 2015; Thomas, 2006). This method involves first coding and then categorising the raw data, from which key themes are identified. A framework is developed based on these themes and processes. The framework should produce three to eight summary categories that capture, and are assessed to be the most important, themes arising from the raw data (Thomas, 2006).

First, recordings were anonymised and transcribed. Completed transcriptions were reviewed and checked for errors. Filler words (e.g. 'um', 'you know', 'like') were removed to assist readability and data analysis (Cai and Richdale, 2016). Transcriptions were imported into NVivo 11 Software (QSR-International, 2015) for coding and analysis. Questions from the focus group guide were used to initially categorise the data. The second author then coded all transcripts into themes and subthemes using NVivo. These codes and themes were reviewed by the

**Table 1.** Participant characteristics.

| Variable                                 |                     | Group                            |                     |                     |                                   |
|------------------------------------------|---------------------|----------------------------------|---------------------|---------------------|-----------------------------------|
|                                          |                     | Trainees                         | Support staff       | Co-workers          | Family                            |
| <i>n</i> (% male)                        |                     | 9 (89% male)                     | 7 (29% male)        | 6 (67% male)        | 6 (33% male)                      |
| Age: <i>M</i> ( <i>SD</i> ), range years |                     | 23.97 (3.00), 19–29              | 36.83 (8.52), 25–51 | 42.21 (6.46), 33–52 | 43.92 (13.89), 24–55 <sup>a</sup> |
| Highest education: % ( <i>n</i> )        | Some secondary      | 11% (1)                          | –                   | 17% (1)             | 17% (1) <sup>a</sup>              |
|                                          | Completed secondary | 11% (1)                          | 14% (1)             | 33% (2)             | 17% (1)                           |
|                                          | Certificate         | 33% (3)                          | –                   | 33% (2)             | 17% (1)                           |
|                                          | Diploma             | –                                | 14% (1)             | 17% (1)             | –                                 |
|                                          | Bachelor's degree   | 44% (4)                          | 71% (5)             | –                   | –                                 |
|                                          | Postgraduate degree | –                                | –                   | –                   | 17% (1)                           |
| Living arrangements: % ( <i>n</i> )      | Spouse/partner      | 11% (1)                          | 43% (3)             | 83% (5)             | 100% (6)                          |
|                                          | Alone               | 22% (2)                          | 14% (1)             | 17% (1)             | –                                 |
|                                          | Parent(s)           | 67% (6)                          | 14% (1)             | –                   | –                                 |
|                                          | Relative            | –                                | 14% (1)             | –                   | –                                 |
|                                          | Other               | –                                | 14% (1)             | –                   | –                                 |
| Prior employment: % ( <i>n</i> )         | Unemployed          | 44% (4)                          | –                   | –                   | –                                 |
|                                          | Part time           | 33% (3)                          | –                   | –                   | –                                 |
|                                          | Full time           | 22% (2)                          | –                   | –                   | –                                 |
| Prior work supports: <i>n</i>            | Received            | 0                                | –                   | –                   | –                                 |
|                                          | Desired             | 3                                | –                   | –                   | –                                 |
| AQ: <i>M</i> ( <i>SD</i> ), range        |                     | 28.88 (3.87), 22–34 <sup>b</sup> | –                   | –                   | –                                 |
| W-ADL: <i>M</i> ( <i>SD</i> ), range     |                     | 32.63 (1.60), 29–34 <sup>b</sup> | –                   | –                   | –                                 |

SD: standard deviation; AQ: Autism Spectrum Quotient; W-ADL: Waisman Activities of Daily Living scale.

<sup>a</sup>Age and education for family members: *n* = 4; *n* = 2 participants declined to complete demographic data.

<sup>b</sup>Trainees: *n* = 8; *n* = 1 participant declined to complete the AQ, W-ADL.

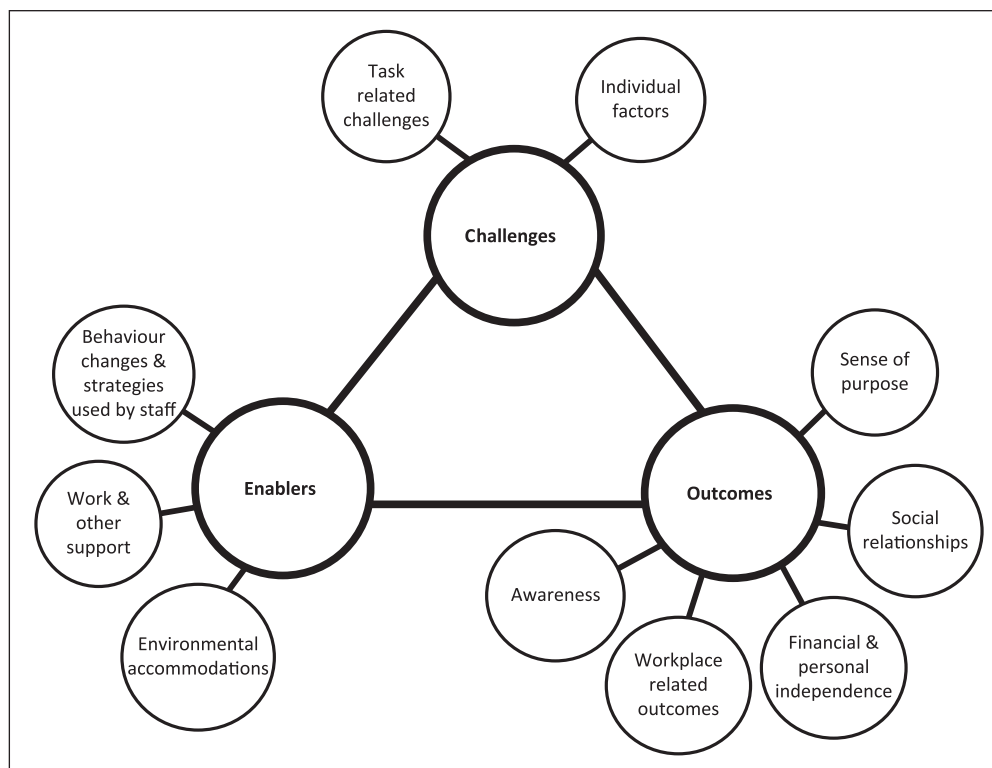
first author and compared against notes taken during the focus group to identify any errors or misinterpretations. Differences were resolved through discussion and amended. Blinded inter-rater agreement checks by an individual not familiar with the research aims were applied to all transcripts to assess fit of coding to themes and subthemes, resulting in 95% agreement between raters (*n* = 1516 phrases reviewed). A framework was constructed based on the three major themes identified, and was used to organise and report the key findings. A draft of the results was distributed to a volunteer representative from the trainee, co-worker and support worker focus groups for review to ensure our interpretations corresponded to their personal experiences (Thomas, 2006). Specifically, the representative was asked to inform the researchers of anything that appeared to be misrepresented, and whether the overall reporting was consistent with their experiences, and of their recollection of the focus group discussions. No discrepancies were identified

and the representatives confirmed that the results reflected both their experiences and recollection of the focus groups.

## Results

### Participant characteristics

Participant characteristics are provided in Table 1. All participants reported speaking English at home. The majority identified as Australian (84%) with the remainder identifying as Filipino, Indian, English and Malaysian (4% each). Seven trainees had completed post-secondary qualifications, including four with Bachelor's degrees. Six of the trainees were living with their parent(s). Prior to commencing the programme, three trainees had worked part time (*M* = 8.33, standard deviation (*SD*) = 0.58, range = 8–9 h/week), two were employed full time (40 h) and four were unemployed. Three individuals who were employed



**Figure 1.** Thematic map of employment experiences.

previously indicated they would have liked, but did not receive, supports for their ASD symptoms at work.

Eight trainees completed the AQ and W-ADL. Six returned a score over the cut-off (26) for ASD on the AQ; two returned scores just below the cut-off (22, 25). No assessment of intellectual functioning was available; however, all participants were functioning satisfactorily in their roles as software tests analysts and, as stated above, most had completed some form of tertiary education. Scores on the W-ADL, which is strongly correlated with intellectual functioning (Maenner et al., 2013), suggested a high degree of independence.

### Focus groups

Three main themes comprising 10 subthemes were identified (Figure 1). The main themes included factors that facilitated success at work (*Enablers*), factors that were challenging or created barriers to success at work (*Challenges*), and programme outcomes (*Outcomes*). Table 2 provides the source and frequency of responses for main and subthemes by participant group. Trainee word count was analysed to determine individual contributions to the focus groups. Contributions for each of the nine trainees ranged from 3% to 23% ( $Mdn=9.8\%$ ); individual word counts ranged from 449 to 3481 ( $Mdn=1484$ ,  $M=1691$ ,  $SD=1084$  words), confirming that all trainees contributed to the focus group discussions

although individual contribution levels varied. Themes and subthemes are discussed in detail in the next section; where results are divided by theme and represent information garnered across groups.

### Enablers

Trainees identified organisation support, advice from co-workers, supportive leadership, allowing environmental modifications and presence of the consultant as factors that facilitated success at work. Enablers identified by co-workers and support staff included environmental modifications, changes to their own behaviour and strategies that facilitated coping, while family members identified the opportunity for their trainee to work in a structured team environment, the level of organisational support and opportunities for them to be involved (e.g. being invited to information sessions). Other factors identified by participants included being providing with plenty of notice of upcoming work tasks, opportunities to take breaks and individual factors such as motivation and having strategies to manage distress.

*Work and other support.* Trainees discussed the support provided by co-workers and support staff. The extract below highlights the role of appropriate and positive feedback and the stress associated with the anticipation of negative feedback:



**Table 2.** Concepts and categories associated with the main themes and areas, by group (N=28).

| Theme      | Area                                   | Source <sup>a</sup> |           |         |        |       | Reference <sup>b</sup> |           |         |        |       |
|------------|----------------------------------------|---------------------|-----------|---------|--------|-------|------------------------|-----------|---------|--------|-------|
|            |                                        | Frequency           |           |         |        |       | Frequency              |           |         |        |       |
|            |                                        | Trainee             | Co-worker | Support | Family | Total | Trainee                | Co-worker | Support | Family | Total |
| Enablers   | Behaviour changes, strategies by staff | 0                   | 6         | 4       | 0      | 10    | 0                      | 18        | 8       | 0      | 26    |
|            | Work and other support                 | 7                   | 1         | 1       | 1      | 10    | 10                     | 1         | 1       | 1      | 13    |
|            | Environmental accommodations           | 2                   | 4         | 1       | 0      | 7     | 2                      | 9         | 2       | 0      | 13    |
| Challenges | Task-related challenges                | 4                   | 1         | 0       | 0      | 5     | 6                      | 1         | 0       | 0      | 7     |
|            | Individual factors                     | 4                   | 3         | 3       | 2      | 12    | 5                      | 5         | 3       | 3      | 16    |
| Outcomes   | Awareness                              | 1                   | 2         | 1       | 0      | 4     | 1                      | 3         | 1       | 0      | 5     |
|            | Workplace outcomes                     | 0                   | 5         | 0       | 0      | 5     | 0                      | 11        | 0       | 0      | 11    |
|            | Financial and personal independence    | 7                   | 0         | 0       | 3      | 10    | 9                      | 0         | 0       | 4      | 13    |
|            | Social relationships                   | 6                   | 0         | 0       | 3      | 9     | 7                      | 0         | 0       | 4      | 11    |
|            | Sense of purpose                       | 6                   | 0         | 0       | 3      | 9     | 7                      | 0         | 0       | 5      | 12    |

<sup>a</sup>Source refers to the number of people who mentioned this concept within their responses.

<sup>b</sup>Reference refers to the number of times this concept was mentioned across all interviews.

People here are great without a doubt ... we have been given the confidence to be able to speak to the other people ... to get their perspective, [co-workers] have been very welcoming to us, they've been very nice ... they are ready to lend a helping hand and give advice ... they don't say that you've done 'that' wrong, but positive feedback, because some people stress about ... because I do, I stress about negative feedback all the time. (Trainee 1)

Another trainee discussed the role of the consultant and of co-workers having awareness of ASD:

I've had plenty of times to talk to [consultant]. That leadership and that quality of hers filters down to the rest of the team below her ... she's had experience with people [with ASD]. So have several other people working in the office around us and even on different floors; they have all had some experience. (Trainee 2)

One family member commented on the value of organisational support:

The fact that they are taking them under the wing, that they are giving them the training, and then they have [consultant] there for the autism side so that she can liaise and actually help, because [trainee] always has lots of trouble interacting with normal (*sic*) people ... other people don't pick up on the way he is. (Family 1)

A co-worker was initially overwhelmed by the level of support provided to trainees:

I was thinking 'why are all these support staff coming in?' ... then once it got underway ... I started saying 'ok, that's good

that they're there all the time because they can constantly monitor ... keep them on task, make sure they've got something to do or not get distracted, or if there are any personal issues' ... I thought that's pretty good. (Co-worker 1)

Support staff also benefitted from having behaviour reframed in terms of ASD symptomatology:

Just to have someone there who understands autism [and] explains things when certain situations occur ... I would question 'why would they react in a specific manner?' ... after that's been explained, I thought 'Oh, I get a better understanding'. (Support 1)

*Environmental modifications and accommodations.* Several workplace environmental modifications were identified. These included changes to lighting, permitting use of headphones to manage auditory stimulation and locating the trainees close to the co-workers to facilitate interaction. One trainee discussed being permitted to wear headphones on both ears. In his previous workplace, he had been required to have one earphone on, the other off, which, rather than help him to manage auditory stimulation, only made things more confusing:

One thing that really helps me is they relaxed the rule for just having one headphone [on], because at the last place they were strict about it. Ten people around the office talking to distract me and they say 'you can drown it out with music in one'. Now ... there is 11 voices I can hear, that just makes it worse! I get really confused if I have to listen to music and 10 conversations at once. (Trainee 3)

Co-workers also discussed the benefits of workplace flexibility regarding environmental adjustments, reiterated here:

Sometimes some of the people would get really distracted by noise ... so they're allowed to have earphones in which we normally wouldn't have, but for them it's good to help them keep on track. There's a guy that doesn't like the light, doesn't like it too bright, so wherever he sits they just take out a globe to make it more dull (*sic*). (Co-worker 2)

One co-worker discussed the benefits of being in close proximity to trainees, which helped to foster social relationships:

By us integrating probably as well as we have ... we can joke ... we can have a laugh, we can talk about gaming ... got to keep them on track for that one though, when you got something they enjoy they're quite happy to talk about it, but yeah I think that's probably helped us a lot [to] sit next to each other. (Co-worker 3)

Another co-worker discussed a planned relocation during a restructure, and how the plan was revised to avoid disrupting the programme:

You do need to have a bit more forward-thought about what you're doing with your planning ... lots of teams got mixed around and shifted ... our team was going to be part of that until somebody raised the question of 'we've got these guys in here, we want them to succeed ... is it appropriate to be shifting everybody around and upsetting the flow?' It [relocation] was re-assessed and decided that it was actually not a good idea to do it. (Co-worker 2)

The introduction of a chart to help trainees manage breaks was also identified as useful:

At the start they were just having their lunch break ... whenever they felt like ... so the support staff, they've got that, you've probably seen it, the chart where they sign themselves out and in, just gives them a bit more structure, so they know ... it's lunch time now so they go to lunch and they know they've got to come back in time. (Co-worker 2)

**Behaviour changes and strategies used by staff.** Organisational behaviour changes included inviting trainees to social events, providing extra time to adjust to the work environment, modifying work allocations, providing clear instructions, acceptance and awareness of individual differences, and redirecting trainees if they become distracted. One of the subthemes most discussed related to changing styles of communication to reduce misunderstandings, such as being mindful of sarcasm and literal interpretations, as the following examples from two co-workers highlight:

The language and communication was a concern for everyone ... say you make some 'off-hand' comment and they take it literally and get distracted from whatever they had to be doing ... for quite some time. (Co-worker 4)

Changing the way I talk to them ... being very concise in what I want instead of using my sarcastic way ... that doesn't work ... it's going to be taken literally instead ... it's just getting used to it – saying what I mean to be done. (Co-worker 5)

## Challenges

Trainees were most affected by factors associated with job tasks, such as learning new processes, and frustration associated with ongoing problems with the computer network which prevented them from completing their tasks. Trainees also discussed individual factors including time management, organisation problems and maintaining attention. In contrast, co-workers and support staff focused on social difficulties and distractibility as being the most significant barrier to trainees' success at work. Family members discussed being distracted by phones, not managing work-related stress and idiosyncratic communication styles which could be perceived as blunt or frank, as challenges the trainees needed to overcome to be successful at work.<sup>2</sup>

**Task-related challenges.** One trainee described his frustration locating the correct access code to enable him to complete his task:

You need a code and most of the time we have to remember them or dig them up or look for them ... then you get lost and you waste more time finding out where you are, and so it's pretty painful. (Trainee 4)

Another trainee expressed frustration with computer network problems and not knowing when it would be back online:

They can sometimes go down for days or hours or minutes you don't know how long they'll be out for so you sit at your desk and you watch the system and wait for it to come back up ... sometimes [it] will be back in about an hour ... other times we just have to wait and twiddle our thumbs and wait and it can get quite annoying. (Trainee 2)

One co-worker noted that the trainees seemed to take this inconvenience of network faults personally:

They don't like it when the system goes down. They take it personally 'Oh, I can't get anything done because I keep hitting a firewall and getting this defect'. I said to them your job is to find defects, so you're not actually slowing down by finding defects, it's your job. (Co-worker 1)

Frustration with the computer network was also identified as problematic by family members:

One little thing that does frustrate [him] is when they don't have anything to do ... it's just as stressful ... and he's frustrated. (Family 2)

This family member noted that blunt or frank communication styles can be perceived by others as rude or offensive:

People on the autism spectrum tend to just deliver information not realising ... the way you present it could be offensive. I do remember [him] giving compliments, but they really weren't. (Family 3)

*Individual factors.* Factors, including time management, attention and coping with change, were identified as other barriers to workplace success. One trainee discussed doing overtime, which subsequently disrupted his evening routine:

One night I did overtime to get something done, but then that threw off my catching my bus, which then threw off some other things I had planned that night ... you have that flow and if something disrupts it you kind of get annoyed. (Trainee 5)

One trainee discussed difficulties maintaining attention, which he attributed to attention deficit hyperactivity disorder (ADHD):

I also have ADHD which makes it extremely hard to concentrate on very large or very small tasks, they've got to be just the right size. Too big and my mind is seriously overwhelmed, too small and my mind doesn't want to put any focus to it because it will be over and done with too quickly. (Trainee 6)

In addition to phones and technology, social interactions negatively affected performance and distracted trainees:

It is a bit compulsive ... they are actually looking for any opportunity to interact socially, which is fantastic to develop their social skills, but if they're off task too much it becomes a problem for productivity. (Support 2)

One of the most discussed issues was trainees not following normative or expected social behaviour, for example, when queuing for an elevator:

Sometimes the lift was a bit slow and so there'd be fifteen people waiting for a lift ... they'd see the door open and they'd just walk ahead, so it was just etiquette ... just minor things ... but for people like us we might go 'we were here first', you know, you wait your turn to get into the lift when there's twenty people waiting. (Co-worker 6)

One family member raised concern about managing stress and the behaviour associated with becoming stressed at work:

I think one of my concerns was just how well supported they were as far as behaviour support ... because [name] is not good at picking up his own stress cues ... in the past, if he's been stressed he would just be on his trigger and just go off and ... just does not pick it up. (Family 4)

## Outcomes

The final main theme that emerged from the focus groups related to outcomes. Overall, trainees, staff and family members reflected positively on a range of outcomes associated with their participation in the programme, as described below.

*Workplace-related outcomes.* Co-workers discussed the quality of work from the trainees, commenting on their ability to detect errors that had been missed previously, and compared them favourably to other workers with many more years' experience and training:

They [trainees] are so particular, they are picking it up ... we had been doing some regression testing in areas that we hadn't done in years and they'll pick it up ... and it should have been fixed years ago. (Co-worker 5)

Another co-worker spoke favourably of the trainees' dedication to their work compared to casual contract workers:

There's a difference of attitude ... these guys really want to make something out of this ... they see it as an opportunity ... they really apply themselves well, whereas other contractors probably may come in saying this is just another job. (Co-worker 2)

The ability to view problems differently was viewed as a benefit to the organisation by this co-worker:

I can only see positives from what we are doing here as an organisation, and ... for [the trainees] too, getting into the work place and being able to utilize their talents. This is what we do, we want to test everything and look at it from different perspectives, and this is what [the trainees] are bringing to the table ... there's nothing but positives. (Co-worker 3)

*Awareness.* The programme provided co-workers an opportunity to get to know and work alongside the trainees, increasing their own awareness and understanding of autism. They also reported feeling proud of the achievements made by the trainees, and their progress within the work environment:



I've really enjoyed seeing the progression ... [he] would hardly ever talk to me or many people, but now when he's in the kitchen and I say 'hi' to him, he takes his earphones off and says hello back so it's just, I have these little wins and whenever one of them does something sort of really nice actually I mention it ... I've gotten just as much out of it as they have so ... it's been good. (Co-worker 6)

The above sentiment was also reflected in the comments of a support staff regarding the impact of the programme on co-workers and the organisation:

It's changing people and it's changing their perceptions, the spin offs have been incredible to the [staff] around us. (Support 2)

A trainee similarly commented on what he had learnt about others with ASD as a result of his participation in the programme:

I've also learnt a lot about people on the spectrum ... before starting this job the only person I knew on the spectrum was me ... its taught me a lot about me, with different aspects of people who have Aspergers or Autism that I wasn't previously aware of ... other things I've learnt about myself which are linked to the fact that I'm on the autism spectrum ... so that's on top of all the stuff I've learnt for the job specifically. (Trainee 2)

*Sense of purpose.* Parents and trainees spoke about the confidence and pride brought by participating in the programme. Below, this trainee spoke about an increase in self-esteem resulting from being able to tell people about the job:

The change for me has been [a] great increase in self-esteem relating to other people. That helps, what you do. (Trainee 3)

Similarly, a family member spoke about her son 'coming out of his shell':

One of the things is [him] coming out of his shell more ... than before he was employed in this program. It is probably one of the biggest things that I have noticed ... this has certainly brought him right out ... his personality right out, which is absolutely fantastic. (Family 3)

One trainee spoke about the sense of purpose and achievement associated with having employment, despite the challenges:

The job provides a purpose ... you're looking forward to getting up in the morning, to going to work ... it is challenging yes, sometimes stressful ... but in the end I know that I've done good. (Trainee 4)

*Financial and personal independence.* Trainees discussed the personal and financial independence as a result of their employment:

Since going full time [I'm] not on [welfare] because I earn too much, so that's had a significant impact on life, so financially I'm able to support myself. I'm renting my own house, I'm paying my own bills. (Trainee 2)

Another trainee spoke about his ability to contribute to the household expenses and his increased independence:

[In my] previous job I was getting paid the minimum wage ... which wasn't much, barely enough to live on. I was barely able to keep my car serviced ... [now] I'm able to have a lot more money to become more independent ... instead of becoming a financial burden I actually became a significant augmentation to the house income. (Trainee 4)

Increased independence following participation in the programme was echoed by one family member:

I can't remember before him ever brushing his hair, even as a teenager, [it] was only if we brushed it. ... his personal hygiene was even suffering and lacking whereas every morning now he's up ... he sets two alarms because he likes to stay in bed but I don't get him up ... he does get himself up, which is a good thing. (Family 4)

*Social relationships.* Trainees and family members reported improvements in social relationships, both with work colleagues, and within families, as exemplified by one trainee:

It has helped me change quite a bit. Before here I was anti-social and mostly stayed at home 90% of the days, never go out except when I had to. Now I tend to spend time out in town and around, hang out with friends a lot more, and [I'm] quite social at work. (Trainee 6)

The increased opportunities for developing social relationships are also echoed in the comment below from a family member:

He's found a best mate, he really has ... [we] had them all over at our house just to get together outside of work. And they really do, they understand each other and support each other. (Family 3)

Two family members spoke about the positive impact on their relationships with their family member at home:

When he comes home for dinner I get a hug and a hug and a kiss before he leaves again ... he'd just come up to the kitchen and give me a hug, it's just lovely. (Family 5)

He would come home from work here and would talk to his sister, which was a big thing. Before ... we got the grunt and the moan ... [now] he comes randomly to talk to his sister ... that's a big win; communication level has gone beyond the grunt. (Family 4)

## Discussion

The overall aim in conducting this qualitative study was to better understand transition to work from the perspectives of individuals with ASD (trainees), family members, and their co-workers and support staff. We were particularly interested in factors that were challenging and those that supported success at work. Consistent with previous research (Baldwin et al., 2014; Howlin et al., 2004; Roux et al., 2013; Taylor et al., 2015), the majority of trainees were previously either unemployed or engaged in part-time employment that was not well matched to their skills and abilities (despite 77% having post-secondary qualifications) prior to their engagement in the programme. While one trainee was married and two lived independently, most (67%) lived with one or more parents, despite reporting a high level of daily living skills, a finding also consistent with other studies (Gray et al., 2014; Shattuck et al., 2012a).

Our sample was characterised by a gender imbalance, with only one female trainee participating in the focus groups. At the time of writing, the programme as a whole currently employs 45 individuals with ASD throughout Australia, with only five (11%) females. This gender imbalance could reflect a lower employment rate among females with ASD compared to males (Howlin et al., 2013; Taylor and Mailick, 2014). However, it could also reflect the typical 4:1 (M:F) gender ratio found in ASD (Baron-Cohen et al., 2001; Klin et al., 1995) combined with female underrepresentation in Science, Technology, Engineering and Mathematic (STEM) fields more broadly. In Australia, only 16% of people employed in STEM jobs are female (Office of the Chief Scientist, 2016).

To address our study aim, we elicited narratives from trainees with ASD, as well as members of their support team, their co-workers and their family members. The three main themes included challenges, enablers and outcome-related factors. In all, 10 subthemes that were aligned with the main themes were subsequently identified. Challenges were associated with task- or individual-related factors. Strategies used by support staff, environmental modifications and organisational support were all identified as factors that facilitated success at work. The outcomes included individual factors such as independence and sense of purpose, positive social and relationship outcomes, task-specific outcomes (e.g. work quality) and increased awareness about ASD.

Trainees were most concerned with technical difficulties that frustrated their ability to complete their work tasks. Co-workers, support staff and family members described symptomatic communication difficulties, such as literal interpretation (Frith and Happé, 1994; Mitchell et al., 1997), among the barriers that needed to be overcome in the workplace. Nonetheless, trainees expressed pride in their work and reported that it provided them with

a sense of purpose. Family members talked about improved relationships at home and the increased opportunities for socialisation, and co-workers and support staff reported feeling proud about what the programme and the trainees brought to their workplace.

It has been suggested that organisations must be willing to recognise the talents of individuals with ASD and also be willing to actively participate in their adjustment to engender success (Giarelli et al., 2013). Moreover, employer and co-worker attitudes and understanding are cited as two of the most significant barriers to success (Chen et al., 2015; López and Keenan, 2014). We found that co-workers who worked closely alongside the trainees developed positive attitudes and understanding of their colleagues with ASD, which may well have contributed to the trainees' success at work, including their feelings of being accepted, their confidence and their enthusiasm for their work. The inclusion of dedicated support staff, in particular the inclusion of an individual with experience working with individuals with ASD, emerged as an important ingredient of the programme. This is consistent with previous research indicating the benefits of having a mentor to support individuals with ASD during transition phases (Giarelli et al., 2013).

Consistent with previous research, sensory and environmental issues affected some of the trainees at work (Giarelli et al., 2013; Landon et al., 2016). Environmental accommodations, such as dimming a light or permitting individuals to wear headphones, proved effective in circumventing problems arising from sensory sensitivity. Trainees also reported being significantly disrupted by unpredictable technical difficulties. Research has shown a relationship between intolerance of uncertainty, sensory sensitivity, insistence on sameness and anxiety in individuals with ASD (Wigham et al., 2015), which may go some way towards explaining the salience of this factor; however, this explanation is necessarily speculative at this point and requires further research.

Not only were trainees motivated to maintain a high standard of work, they also showed insight into the work environment and to some of the challenges posed by ASD symptoms. One trainee commented on the insights into his own symptoms that he had gained by working with others like him, who also faced similar challenges. Trainees socialised with each other both at work and outside of work, suggesting that work may provide increased opportunities for social interaction. This contrasts with the social isolation experienced and reported by many young adults with ASD (Orsmond et al., 2013).

This study, and the employment programme described herein, addresses some of the priorities identified by a recent Special Interest Group (SIG) into transition and employment which brought together around 120 international delegates at the 2015 International Meeting for Autism Research (IMFAR). The SIG identified the need to

generate research, to involve diverse stakeholders, to build employer capacity by proactively engaging employers and multi-sectoral industries which better link employers to people with ASD, and to create supports to enable sustained employment (Nicholas et al., 2016). Moreover, the SIG identified the challenges faced by adults with ASD who struggle to secure employment, particularly that which is meaningful and stable. Individuals in the current programme received competitive salaries and, as our study suggests, had meaningful and relatively stable employment. As indicated by Nicholas et al. (2016), we found that functioning and productivity at work can be affected by the unique characteristics of adults with ASD, including sensory needs, restricted interests and atypical social communication. The degree to which these characteristics affect work, however, can be minimised through provision of appropriate support. Moreover, some of these unique characteristics may be advantageous, as indicated by the quality of work output reported.

While we did not specifically address this issue, it may also be that support strategies which benefit individuals with ASD are also beneficial for employees without ASD. For example, strategies such as reducing unstructured time, direct communication and maintaining schedules are effective techniques for supervising employees both with and without ASD (Hagner and Cooney, 2005).

More work is needed to identify the long-term outcome of the current programme. This might include the impact on mental health and well-being (e.g. quality of life), whether the programme is successful in developing desirable characteristics (e.g. independence), or skills that increase the individual's employability (e.g. specific technical or interview skills). Furthermore, the impact of the programme on the organisation must also be examined. It is possible that the high level of organisational commitment required to implement and maintain the programme, which includes the additional employment of dedicated support personnel, may impact its long-term sustainability. Potential harmful effects of the programme must also be considered. For example, the impact on individuals who applied but were not successful in gaining employment, or who do not progress past the mandatory probation period (6 months).

It is interesting to note that challenges tended to be work or individual-specific, whereas enablers to success were programme-specific. This bias was reported across participant groups, and may reflect unintentional bias of the interviewer and/or coding process. Attribution theory (Weiner, 1986) would indicate that people who do not expect success are more likely to attribute instances of success to external factors, and failure to internal or personnel characteristics. While speculative, it may be that the high degree of support provided to trainees, and also their employment history, may contribute to this attributional bias. Thus, one priority of the programme should be to

increase independence and fully integrate trainees into the mainstream work environment, thereby developing their skills to a point where they are no longer reliant on the programme and accompanying supports. This may lead to a more appropriate and proportional attribution of success to the skills and abilities of the trainees themselves; increase the likelihood of trainees feeling able to apply for future positions where ASD supports are not in place and; moreover, may be an important indicator of the maturation of the programme.

A strength of our study was that we included individuals with different experiences of the trainees, who thus brought different perspectives, enabling us to triangulate our findings. However, it is also important to acknowledge that generalisability of our results is limited as data were collected from one trial site in a programme specifically designed to accommodate individuals with ASD, based within one industry (Information Technology). The programme is currently operational at several other locations throughout Australia. Thus, it would be beneficial to conduct a second layer of focus groups to see if similar themes emerge at other sites. It would also be beneficial to compare this programme with different programmes that also support people with ASD who are entering the workplace. Generalisability is also affected by the high level of structured support provided to trainees which may not be present in other programmes. Notwithstanding this point, it is our opinion that many of the themes identified here will be transferable to different work environments.

Participants may have been unwilling to speak about certain topics, such as challenges, problems or other negative aspects of the programme, or may otherwise have been inhibited by participating in focus groups. Nevertheless, they all signed consent and were provided the option of individual interviews, which none chose, and procedures (e.g. small group size) were put in place to encourage participation. The analyses of word count confirmed that all trainees contributed to groups; however, there was variation at the individual level indicating some trainees did contribute more than others. It is also possible that those individuals who chose to participate in the study may have been more positive about the programme (one trainee did not consent to the study). The possibility of tempered or overly positive responses to questions due to the group environment, or for other reasons, therefore needs to be acknowledged as a limitation of the study. Also, while participants completed the AQ, which is a screening questionnaire, we did not conduct independent assessments to confirm ASD diagnosis.

In conclusion, this study represents the transition to work of a small group of individuals within a specialised employment programme, and the perspectives of those who live with, support and interact with them on a daily basis. Some of their challenges, but also their successes, have been described here. It is hoped that these insights

foreshadow the continued development of organisational environments that are flexible and accepting of diversity, that provide employment opportunities and, moreover, that recognise and value the unique attributes of *all* employees.

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### Notes

1. Monetary values are as reported in the original manuscripts and may not reflect current currency values.
2. While family members were asked about previous work experiences in the transition phase of the focus groups, results presented here pertain to the current work environment only.

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**Appendix 1. Focus group guide.**


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|--------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Opening      | [T, C] Please introduce yourself, what your current job role is and what you most enjoy doing when you're not at work.<br>[F] Please introduce yourself, what's one of the things that you most admire about your family member on the autism spectrum.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| Introductory | [T] What is a previous job you have had, and a good or not so good experiences in that job?<br>[C] What did you know about autism, or what are some of your previous experiences with individuals on the autism spectrum, prior to being involved in this project?<br>[F] Thinking back to when your family member first became involved with the programme, what were your some of your first thoughts, expectations or impressions about the programme?                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
| Transition   | [T, C] Thinking back to when you first became involved with the programme, what were your some of your expectations? What were your some of your apprehensions?<br>[F] Can you talk a little about some of your family member's previous work experiences? What are some of the things that make it difficult for your family member to participate in the workplace?                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| Key          | [T] What are some of the goals you want to achieve in your current position? Thinking about your current position, what are some of the things that have helped you to achieve your goals at work? Thinking mainly about your current position, what are some of the things that have made it difficult or that have prevented you from achieving your goals at work? How has the transition to employment impacted your life outside of work, your relationships with others and the activities you typically do?<br>[C] What accommodations, either personally or with work systems, have you or the organisation made to accommodate your colleagues on the autism spectrum? What do you think are some of the things that have most helped your colleagues on the autism spectrum in the workplace? What do you think are some of the things that you think have been most difficult or challenging for your colleagues on the autism spectrum in the workplace?<br>[F] What are some of the things you were or are most worried about regarding your family member being employed in the programme? Probe: have any of these concerns been alleviated? If YES: was there anything specific that helped to alleviate your concerns? If NO: is there anything the organisation could have done differently to address your concerns? From your perspective, what are some of the benefits for your family member of being involved in the project? What are some of the things done by the organisation that you think have been most helpful for your family member to transition to work? Probe: what are some specific examples of the support your family member is receiving? Probe: does this differ from the support given from previous employment experiences? From your perspective, what are some of the things that you think haven't been helpful, or that could be done differently by the organisation? |
| Reflection   | [T] Tell me about your work: do you enjoy it; was it what you expected; things you've learnt; challenges; difficulties related to the tasks; any advice for others thinking about the programme?<br>[C] What has it been like working with the team: quality of work; social; challenges; difficulties?                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| End          | [T, C, F] If you could give some advice for people in the future implementing a programme like this, what would it be?                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| Summary      | <i>2- to -3-min summary of the main topics. Check summary reflects participant experience</i>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
| Check        | [T, C, F] We want you to help us evaluate the programme. Is there anything that we've missed? Is there anything you came wanting to say that you didn't get a chance to say?                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |

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T: trainee; C: co-worker, support staff; F: family member.