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**Vocational training programs, transition programs and work experience placements for employment of young adults with intellectual disability: A systematic review & a description of employment patterns and day occupations of young adults with intellectual disability residing in Queensland**

Sophia Davidson  
*Edith Cowan University*

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**&**

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Sophia Davidson

Bachelor of Science (Occupational Therapy) (Honours)

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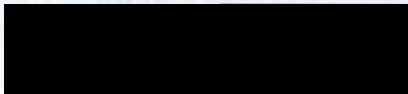
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placements for employment of young adults with intellectual disability: A  
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**&**

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with intellectual disability residing in Queensland**

Sophia Davidson

A report submitted in Partial Fulfilment of the Requirements for the Award of  
Bachelor of Occupational Therapy Honours,  
Faculty of Computing, Health and Science,  
Edith Cowan University

Submitted October, 2011

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Vocational training programs, transition programs and work experience  
placements for employment of young adults with intellectual disability: A  
systematic review

Sophia Davidson

## **Vocational training programs, transition programs and work experience placements for employment of young adults with intellectual disability: A systematic review**

### **Abstract**

**Objective:** To review the research examining the effectiveness of vocational training programs, transition programs and work experience placements and describe their impact on work and employment attainment and maintenance for young adults with intellectual disability.

**Method:** Electronic searches of six databases and manual searches of references lists locating all available evidence of programs and interventions to assist young adults with intellectual disability to find paid employment. Interventions described as vocational training, work placements and experience and transition programs aimed at securing employment were included. Two reviewers undertook data extraction and quality assessment and a systematic review was possible.

**Results:** Nine articles met the inclusion criteria reporting on young adults with intellectual disability with a collective total of 325 participants. Authors described the supports and interventions as job skills training, preparation for post-school, transition programs, transition to adult services, and vocational/training programs.

**Conclusions:** The effectiveness of transition programs aimed at employment, job skills training and work experience placements and their positive impact on the employment outcomes of young adults with intellectual disability is supported by the evidence. Small samples sizes and the qualitative nature of research meant only a systematic review was possible, and no generalisations to the wider population could be made. Further studies with larger sample sizes and longitudinal follow-up is needed to further understand the effectiveness of these programs.

**Keywords:** *intellectual disability, young adults, transition programs, work, employment, vocational or job skills training, work experience placements, systematic review.*

## **Vocational training programs, transition programs and work experience placements for employment of young adults with intellectual disability: A systematic review**

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### **Abstract**

**Purposes:** To review the effectiveness of school to post-school transition programs for young adults with intellectual disability and their impact on community participation, friendships and quality of life.

**Methods:** Electronic searches of six databases and manual searches of reference lists were conducted to obtain evidence of programs supporting the transition of young adults with intellectual disability from school to post-school. Transition programs or services and postsecondary education programs targeted at increasing participation and peer interaction were included. Two reviewers undertook data extraction and quality assessment. A systematic review was possible.

**Results:** Nine articles were reviewed, with a total of 573 participants, reported on the impact of the transition process and programs from school to post-school on the young adults with intellectual disability including the perceived barriers and facilitators to the transition process. Authors discussed outcomes of transition programs as community participation, friendships and quality of life.

**Conclusions:** School to post-school transition programs appear effective in encouraging community participation, social interaction and, ultimately, positively impact on the quality of life for young adults with intellectual disability. Varying sample sizes and the methodological quality of the studies allowed only for a systematic review. Future research using larger samples to examine the effectiveness of school to post-school transition programs across a variety of settings is required. This research should also examine issues such as the timing of services in relation transition from secondary school.

**Keywords:** intellectual disability, transition programs, work experience, post-school, participation, young adults

### **Introduction**

In 2008, there were over half a million people with intellectual disability living in Australia [1]. Intellectual disability is defined as originating before 18 years of age and characterised by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social and practical adaptive skills [2]. People with intellectual disabilities are often socially isolated and excluded from everyday occupations that the wider population engage in daily including work and employment. The United Nations Enable charter state that persons with disabilities should be enabled, through peer support, to attain and maintain maximum independence, full vocational ability and full inclusion and participation in all aspects of life particularly in the areas

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of health, employment education and social services [3]. Research has reported that people with Down syndrome and other intellectual disabilities do not differ from the general population in their desire to participate in the work force [4]. However in Australia 90% of people with intellectual disabilities are unemployed, compared to only 5% of the general population [5, 6].

The Commonwealth Government currently spends over \$5,849 million dollars on Disability Support Pensions per annum [7]. Despite an abundance of policy documents in Australia and internationally which stress the importance of the inclusion of people with disabilities in the workforce [8-10] they remain poorly represented. Participation in work provides the opportunity for the formation of peer relationships and has been reported to enhance wellbeing [11], while unemployment can lead to poverty, poor mental health and social exclusion [12]. Transition programs aimed at employment, work experience and job skills training are forms of early intervention that can assist young adults with intellectual disability to gain the skills and training required to enter the workforce.

The post school period is often described as a time of great stress for parents and carers of young adults with intellectual disability. This occurs for many reasons including the reported removal of established supports and lack of continuity between supported education (child) and post-school/adult services [13]. Evidence has also demonstrated that contextual factors have the greatest overall impact on the employment of young adults with intellectual disability [14]. These include the services and supports available to the young adult and their parents/carers, who are often required to advocate for the young.

However, further examination of the specific factors that impact on the employment outcomes of young adults with intellectual disability in Australia is necessary. Young adults with intellectual disability often have limited access to opportunities to develop their adult identity such as living independently away from their parental home, further

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education and gaining employment. Work and Employment facilitate identity development through opportunities for occupation and the formation of relationships with others. Employment has many benefits for the individual worker. Research with normative samples of community dwelling adults has highlighted the benefits of work in relation to social inclusion, participation and adaptive skills development [10]. Improved mental health outcomes such as greater self-perceived control, overall life satisfaction and higher self-perceived productivity have been reported as benefits of employment amongst both the normative population and intellectually disabled persons [15]. These benefits are realised by the parents and carers, educators and service provision staff who have contact with the young adult with intellectual disability. Therefore the aim of this review was to examine the effectiveness of existing vocational training programs, transition programs and work experience placements and to describe their impact on work and employment attainment and maintenance for young adults with intellectual disability.

### **Methods**

This review used the standard principles and techniques of systematic reviews [16]. Electronic searches of six databases were used to identify relevant studies for inclusion. Databases searched included Web of Science, ERIC, MEDLINE, PSYCHinfo and CINAHL plus with full text. Each database was searched from the last 15 years to June 2011. The main search terms were Down syndrome or intellectual disability, vocational training, work or employment and young adults. With assistance of a librarian all terms were truncated, expanded and modified to match the database being used. No language restrictions were placed on the searches, however searches were limited to published articles and papers. Reference lists of all relevant retrieved studies were manually searched for key papers.

*A priori* criteria for inclusion of studies were applied first to retrieved abstracts then to the full text of articles if adequate information was not provided in the abstract. Studies were included if interventions were described as vocational training, transition programs, work placements or experience or work or job skills training. The method,

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length and frequency of the programs and the discipline of the program providers were not limited. Participants of the studies were limited to those where youth, adolescents and young adults with an intellectual disability aged 15 to 44. Outcomes of interest included, participation in paid employment, involvement in job skills training and work placements.

### **Assessment of methodological quality**

Two reviewers independently assessed the quality of each study using the Kmet assessment tools for qualitative and quantitative studies [17]. The checklist consists of 10 questions and a rating system to assess the quality of both the reporting and evidence of studies. The reviewers used the checklists to determine the quality of the evidence and reporting itself and articles were rated based on mutual agreement. The reviewers used the calculated score which was converted to a percentage to define the quality as strong (>80%), good (70-80%), adequate (50-70%) or limited (<50%). Articles were not excluded from the scope of this review based on quality due to the limited number of suitable articles available. Discrepancies were resolved through discussion and use of the assessment tools.

### **Data extraction**

Two reviewers independently extracted data from the potential studies using methods outlined in Section 7 of the *Cochrane Handbook for Systematic Reviews of Interventions*. Data extracted included: study design, participant selection methods, study objective(s), sample size, focus of study, main findings and conclusions. Any disagreements were resolved through discussion. Once data were extracted levels of evidence were determined using the National Health and Medical Research Council Guidelines [18].

### **Data synthesis and analysis**

A meta-analysis was not possible given the small number of protocols reported and non-traditional analyses in the majority of articles. A systematic review was instead

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undertaken to summarise findings and provide an assessment of methodological issues. A summary of included studies is presented in Table 1.

### **Results**

Electronic searches located 58 articles from Web of Science, 65 from CINAHL plus with full text, 33 from ERIC, 42 from MEDLINE and 52 from PSYCHinfo for a total of 218 potential articles after accounting for duplicates. Using the stated inclusion criteria, titles and abstracts were reviewed resulting in 209 articles judged as ineligible. Full texts of the remaining nine articles were retrieved and reviewed for inclusion. See Figure One: Flow chart.

All nine articles met the inclusion criteria reporting on young adults with intellectual disability collectively with a total of 325 participants. Authors described the supports and interventions as job skills training, preparation for post-school, transition programs, transition to adult services, and vocational/training programs. Of the included studies five articles were qualitative, two were mixed methods and two were purely quantitative in nature. Data collection methods included participant observations, interviews, surveys/questionnaires, focus and discussion groups.

### **Quality assessment of studies**

The methodological quality of the articles ranged from adequate to strong (see Table 1). Programs aimed at preparing the young adult for transition, post-school services and employment were reported in three of the studies. They were rated from adequate to strong based on the quality of the reporting and evidence using the Kmet qualitative and quantitative review forms. Parental or professional perspectives were examined in five studies and each of these also reported the perceived factors that impacted on employment and transition success of the young adult [19-23]. They too were rated from adequate to strong. One study described the utility of the Self-Determined Career Development Model in achieving employment outcomes [24]. This study was rated as strong.

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Methodological shortcomings of qualitative articles include small sample sizes and limited transferability. These limitations are frequent in qualitative studies as participant numbers are often small when gaining perspectives and experiential data of a group. However, qualitative research is important in gaining an in-depth understanding of the lived experience of the individuals [25]. The methodological limitations of quantitative studies are in the structural biases imposed by the researcher. These may lead to unreliable results and not reflect the true feelings and experiences of the study participants [25]. Overall only some authors reported adequate contextual information, however many failed to which lead to a lower score of methodological quality. Further limitations included, no reference to a theoretical framework or wider body of knowledge, limited usage of verification procedures to establish credibility, data collection and analysis methods were rarely described clearly and systematically and there was limited reporting of reflexivity of the authors account. The one exception was [21] study of transition experiences from parents' perspectives, which reported on all of the Kmet review areas.

### **Interventions**

The intention of this review was to review all available research examining work and employment training, transition and work placement programs for people with intellectual disability, however this was limited by a lack of literature. Three studies described transition programs with the specific outcome being work placement, job skills training and preparation for employment [22, 26, 27]. One described the use of the Self-Determined Career Development Model to establish work-related goals with participants, with success measured by the extent to which participants met their goals [24]. The final five studies reported on the perspectives of the young adults and their parents/carers surrounding the transition to employment from supported education services. [20, 21, 28], examining factors which affected employment motivation for the young adults [19], and the barriers and facilitators to a successful transition. One study described the key information families, educators and young adults needed in order to

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be fully informed and engaged in the transition process of the young adult [23]. Findings from this research could be described in relation to parental perspectives, factors which impact employment, and lack of continuity between the rates of employment among research participants and employment statistics within the wider population of people with intellectual disability.

## **Main findings and themes**

### *Parental/ carer perspectives*

All studies that examined the transition from special education or high school services to post-school/ adult services described it as a time of stress, which had a negative affect on the family unit. For parents and carers this was a time of high anxiety, frustration, and uncertainty. Parents also felt judged by peers and professionals which lead to feelings of disempowerment, reluctance and concerns surrounding the treatment of their young adult by the wider community [21, 22]. Davies reported a parents' comment that their '*entire life was an adjustment*' not just the transition period [21]. Parents, educators and the young adults themselves were reported to be lacking in key information regarding their choices and supports during this period. Many reported feeling uncertain and frustrated by the lack of information available and documentation available to inform them [22].

### *Pressure from peers/professionals regarding choices for young adult*

Parents described the extra pressure they felt from peers, teachers and professionals during this period all of whom felt that they '*knew best*' for the young adult. This often left parents feeling judged by others for their choices regardless of their reasoning and uncertain as the best option for their young adult [20]. Parents reported greatest tension surrounding the choice of independent living for their young adult versus remaining in the family home. Parents reported less judgement surrounding employment options but commented that open employment, although a desirable outcome, was often not a realistic goal for their young adult due to high support needs, behavioural or self-management problems and limited skills [20]. Parents reported being fearful of

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allowing their young adult more independence particularly in money handling as a result of their concern that they would be taken advantage of.

#### *Factors which impact on employment*

Parents and professionals reported many factors that impacted on the employment of their young adult, these can be described in relation to four broad categories of family, personal, service and social factors. The positive family factors which impacted the employment of the young adult included involved parents who advocated for the needs of their young adult [22]. Parental knowledge of the system and supports available was positively associated with employment outcomes [22]. Parents reported that they often had to navigate services alone and parental advocacy was often the only reason engagement continued [21, 22]. Better transition or employment outcomes were achieved when family support was strong and parents were heavily involved in the decision process advocating for their young adult [21, 22, 26].

Personal factors of the young adult with intellectual disability, which positively impact on employment included, better self-management abilities, higher motivation levels, and the young adults themselves wanting and seeking employment. High community functioning abilities and good social/self-determination/communication levels were associated with better employment outcomes [23]. Although factors such as academic ability were expected to affect employment outcomes no evidence of its relationship was found in this review. However factors such as the IQ level, psychosocial functioning and adjustment capacity of the young adult were found to be important factors in one study [28]. Personal factors that negatively impacted the employment outcomes of the young adults were unacceptable behaviour, excessive absences, non-compliance, poor personal hygiene, and poor safety awareness. These were highlighted by supported employment providers as reasons for loss of services or dismissal from employment [23]. Service providers suggested that if educators, youth and parents were aware of these factors they would be better able to make informed choices in relation to



the possible employment outcomes or suitable work placements for the young adult based on their performance in work situations [23].

Service system factors that positively impacted employment outcomes included, better knowledge level of professionals and educators, supporting documentation and transition assessments being conducted during schooling or vocational training [23]. Parents reported that although many providers had developed a transition plan and a summary of performance document to support the specific plans, goals and strengths of their young adult, very few had ever seen this document [23]. It was reported that this documentation should be a 'working document' and follow the young adult from school to adult services, being updated as strengths, and skills changed and grew [23]. A recurrent theme throughout all studies was the lack of continuity between school and adult services. Overall parents reported a lack of information, limited choices in relation to specialist providers, waiting lists and a absence of person-centred practice in service co-ordination [22].

Social factors were described as significantly influencing the transition process. A common theme throughout the research was that young adults did not have access to social development opportunities outside of organised work activities [21-23]. Although social involvement is a reported desirable outcome of participation in employment for young adults with intellectual disability this occurred largely as a by-product of work activities rather than as a result of a specific focus by employers or service providers. Parents also reported that competitive job markets and negative attitudes of employers made employment more difficult for their young adult [22].

*High employment rates among research participants were not reflective of wider population of people with intellectual disability*

Overall the employment rates of young adults with intellectual disability reported in the included studies were not reflective of population data regarding the overall employment rates of this group [6]. This was explained by one study as a reflection of

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the possible effectiveness of the transition program being researched [27]. It could also be attributed to selection bias of participants which often occurs in qualitative research [29].

## **Discussion**

This systematic review found both qualitative and quantitative evidence to support the effectiveness of vocational/training programs aimed at securing employment for young adults with intellectual disability. Collectively this research supports the conclusion that these services and interventions do positively impact on the employment outcomes of young adults who access these services.

Limitations of this review are that research was only located from six databases, although it could be agreed that these databases were most likely to gain quality research in this area. This search was limited to published literature and did not include manual searches of occupational therapy journals, grey literature or conference proceedings.

Due to the qualitative nature of the majority of studies included in this review, generalisations to the wider population are not possible. Therefore further investigations into the effectiveness of job skills training, work placements and experience, and transition programs aimed at employment should be undertaken with a larger cohorts over longer periods.

All parents interviewed reported that the transition from school to post-school services was a time of high anxiety and stress [20-22]. Findings from this review suggest that parents do not receive the support they require from schools or service providers during this difficult period, clinically this reinforces the need for better service delivery models and continued support. Although the importance of early intervention transition programs, job skills training and work experience placements in facilitating employment outcomes for young adults with intellectual disabilities is highlighted in

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existing literature these interventions are often not received or followed to completion. Therefore the emphasis on health professionals, educators, service providers and parents and caregivers of the young adult to press for program continuation and follow-up through all stages of transition is highlighted. The importance of a working document, which follows the young adult from school to adult services and between service providers, is stressed. Service providers should take a holistic approach to services with improved communication and coordinated rather than focusing solely on employment. This would enable parents, carers, educators, service providers themselves and future employers to better provide for the complex needs of the young adult

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## APPENDICES

**Table 1: Description of included studies**

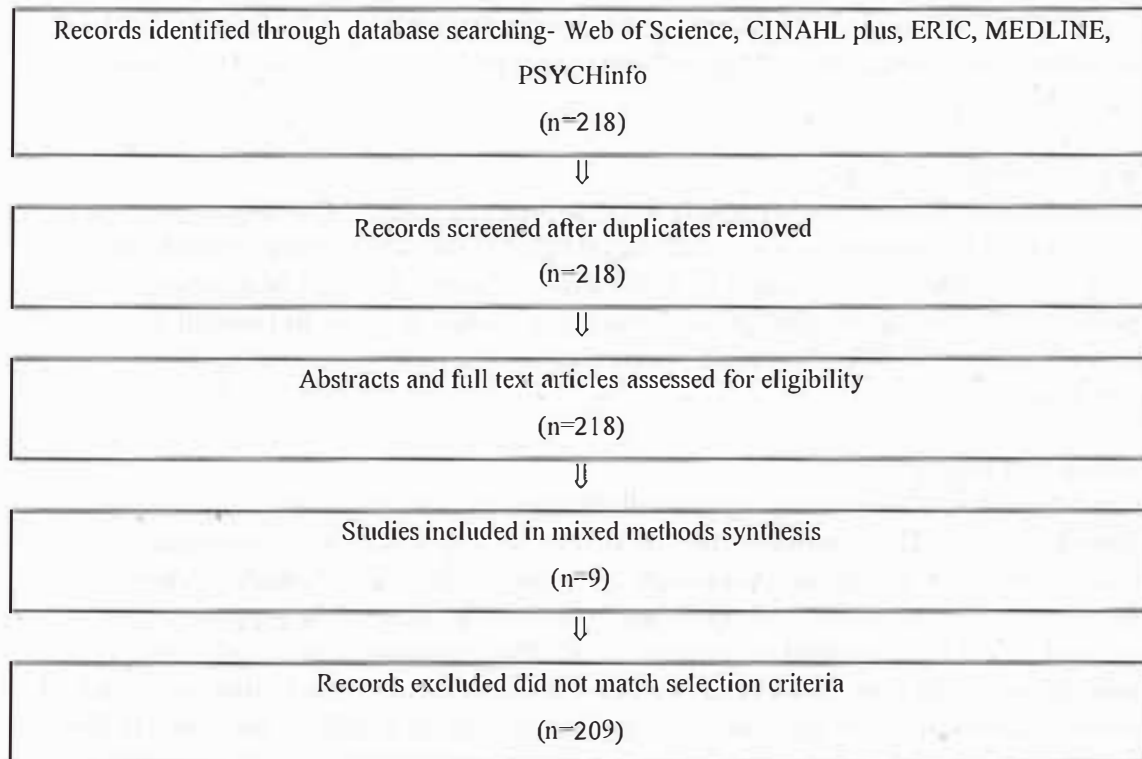
First author, year of publication, country	Design	Inclusion in review criteria	Focus of study	Main findings	Methodological quality
Andrews 2010 United Kingdom (Andrews & Rose, 2010)	Qualitative Focus groups (n=10)	Young adults with intellectual disability Factors affecting employment motivation	Feelings surrounding employment and factors which motivate or deter young adults	<b>Perspectives/factors:</b> Young adults' motivational factors 1. Monetary gain 2. Social aspects 3. Perceived competence Deterrent factors 1. Amount of physical effort involved/required 2. Duration of working day 3. Working long hours 4. Getting up early	14/20- adequate
Butcher 2008 Canada (Butcher & Wilton, 2008)	Phenomenological design, interviews and participant observations (n=6)	Young adults with intellectual disability Transition in search of paid employment	Training for and engaging in paid employment Meaningful activity Critical reflection of state-sponsored program aimed at facilitating social inclusion for disabled youth through attachment to labour market.	<b>Programs:</b> Successful if young adult with intellectual disability is able to assume desired adult roles that are allied with his/her strengths and needs. Meaningful activity is more important than just paid employment.	15/20- good
Clegg 2008 United Kingdom (Clegg, Murphy, Almack, & Harvey, 2008)	Cohort study, interviews and discussion groups of 2-4 people. (n=28)	Young people with intellectual disability and their carers Engagement in employment	Study investigated engagement with inclusion at transition to adult services. Tensions experienced by families and carers regarding inclusion. Inclusion policy-mainstreaming, independent living and employment are discussed.	<b>Perspectives/factors:</b> Families/carers: 1. Tension around employment was reported. 2. Judged negatively regarding their decisions despite their reasons behind them. 3. Work "desirable outcome but unworkable for many youths with intellectual disability". 4. Work experience valued by families. 5. Valued "access to meaningful activity that engaged them". 6. Engagement and relationships were reported as most important outcomes 7. Young adults; felt positive regarding work, young men wanted it.	18/20- strong

First author, year of publication, country	Design	Inclusion in review criteria	Focus of study	Main findings	Methodological quality
Davies 2009 Australia (Davies & Beamish, 2009)	Qualitative Mailed surveys (n=218)	Parents of young adults with intellectual disability School preparation programs for employment	Mailed surveys regarding transition experiences from school of young adults with intellectual disability from parents perspective	<b>Perspectives:</b> Preparation for post-school life and outcomes for young adult and family Lack of post-school options Impact of circumstances on family as a whole	20/20- strong
Devlin 2008 America (Devlin, 2008)	Qualitative Participant observations (n=4)	Young adults with intellectual disability Job performance Employment outcomes	Use of Self-Determined Career Development Model to set work related goals, development of an action plan, implementation of the plan, adjust goals and plans as needed.	<b>Model usage:</b> Achievement of work-related goals. Self-Determined Career Development Model assisted professionals and job coaches in supporting people with intellectual disability in a work setting.	16/20- strong
Gillan 2010 Ireland (Gillan & Coughlan, 2010)	Grounded theory approach, semi-structured interviews (n=12)	12 parents of young adults with intellectual disability Transition into post-school services	Parents perspectives on transition from special education to post-school services for young adults with intellectual disability.	<b>Programs/Perspectives/factors:</b> 1. Meaning of transition process for parents- ongoing process 2. Psychological impact of transition experience- Negative impact- stress, anxiety, frustration, disempowerment and uncertainty. 3. Barriers and facilitators of transition process (family, service and social systems) Family system- reluctance by parents, concerns about young adult handling money and being taken advantage of. Service system- lack of information, lack of alternatives to specialist vocational providers, waiting lists and lack of person-centred-practice during co-ordination. Were however well organised. Social system- competitive Irish job market, negative employer attitudes, loss of disability benefits when working over 20hrs per week and lack of opportunity to develop social networks.	18/20- strong
Luftig 2005 USA (Luftig & Muthert, 2005)	Over-the-phone questionnaire (n=36)	Young adults with special needs who had graduated from a full-time program in a vocational/technology centre.	Patterns of employment and independent living of adult graduates with learning disability and mental retardation of an inclusionary high school vocational program.	<b>Programs:</b> 81% of all respondents were employed, only 68% of respondents with developmental disabilities were employed. They were employed in service industry and factory positions. 95% of respondents with mental retardation were still living with their parents versus only 53% of respondents with learning disabilities. Good employment outcomes perhaps due to quickly moving students through the 'unsettled and exploratory' phases and into the 'focused' phase during which students received specific vocational and job training as well as independent living skills training.	13/20- adequate

First author, year of publication, country	Design	Inclusion in review criteria	Focus of study	Main findings	Methodological quality
Moon 2011 America (Moon, Simonsen, & Neubert, 2011)	Qualitative In person surveys (n=12)	Supported employment providers for young adults with developmental disability. What students, families and educators need to know for transition planning.	Survey Community Rehabilitation Providers (CRPs) regarding their perceptions of the skills, experiences, and information that transitioning youth with developmental disabilities and their families need to access supported employment (SE) services.	<p><b>Perspectives</b> Youth, families and educators need to know:</p> <ol style="list-style-type: none"> <li>1. Recruitment and eligibility for Supported Employment services by Community Rehabilitation Providers.</li> <li>2. Understand that unacceptable behaviour and excessive absences or non-compliance could result in loss of services.</li> <li>3. Differences between school and adult services</li> <li>4. Importance of work experience and a resume or document with work experiences and preferences in detail, to follow the student to the next services provider</li> </ol> <p><b>Factors</b> which lead to employment</p> <ol style="list-style-type: none"> <li>1. Self-advocacy, self-determination, social skills, hygiene, safety-awareness, communication skills and travel training skills should be acquired before leaving high school.</li> <li>2. State provided funding is the only real requirement.</li> <li>3. Summary of performance document was necessary upon exiting the school system. These outlined students goals, supports and future needs, no parents reported receiving a copy of this document.</li> </ol> <p><b>Factors</b> which lead to unemployment</p> <ol style="list-style-type: none"> <li>1. Negative behaviours, poor hygiene, poor safety skills and toileting issues could lead to removal or denial of services.</li> </ol>	15/20- good
O'Brien 2006 United Kingdom (O'Brien, 2006)	Non-clinic community follow up of a cohort of young adults with learning disability/mental retardation. (n=149)	Young adults with learning disability/mental retardation (n=41) in full time independent employment and (n=20) in full time sheltered employment.	Psychosocial functioning and adjustment at transition to adult services.	<p><b>Perspectives</b></p> <ol style="list-style-type: none"> <li>1. Educational and specialist support services need be to geared toward child's assessed abilities and potential whilst also placing highest emphasis on the child's social development.</li> <li>2. Very high number were in full time employment this is not reflected in other literature, suggests that the system in place at the time of the study had its strengths in preparing youth for adult life.</li> </ol> <p><b>Factors</b></p> <ol style="list-style-type: none"> <li>1. Child's IQ was found to be very relevant to his/her development and capacity for adjustment.</li> </ol>	17/20- strong



Figure 1: Flow Chart



## **Disability and Rehabilitation Instructions for Authors**

### **Manuscript Preparation**

In writing your paper, you are encouraged to review articles in the area you are addressing which have been previously published in the Journal and where you feel appropriate, to reference them. This will enhance context, coherence, and continuity for our readers.

### **File preparation and types**

Manuscripts are preferred in Microsoft Word format (.doc files). Documents must be double-spaced with margins of one inch on all sides. Tables and figures should not appear in the main text, but should be uploaded as separate files and designated with the appropriate file type upon submission. References should be given in Council of Science Editors (CSE) Citation & Sequence format (see References section for examples).

### **Structure of Paper**

Manuscripts should be compiled in the following order: title page; abstract; main text; acknowledgments; Declaration of Interest statement; appendices (as appropriate); references; tables with captions (uploaded as separate files); figures with captions (uploaded as separate files). An introductory section should state the purpose of the paper and give a brief account of previous work. New techniques and modifications should be described concisely but in sufficient detail to permit their evaluation; standard methods should simply be referenced. Experimental results should be presented in the most appropriate form, with sufficient explanation to assist their interpretation; their discussion should form a distinct section. Extensive tabulations will not be accepted unless their inclusion is essential.

### **Title Page**

A title page should be provided comprising the manuscript title plus the full names and affiliations of all authors involved in the preparation of the manuscript. One author should be clearly designated as the corresponding author and full contact information, including phone number and email address, provided for this person. Keywords that are not in the title should also be included on the title page. The keywords will assist indexers in cross indexing the article. The title page should be uploaded separately to the main manuscript and designated as "title page" on ScholarOne Manuscripts. This will not get sent to referees.

### **Abstracts**

Structured abstracts are required for all papers, and should be submitted as detailed below, following

the title page, preceding the main text.

*Purpose* State the main aims and objectives of the paper.

*Method* Describe the design, and methodological procedures adopted.

*Results* Present the main results.

*Conclusions* State the conclusions that have been drawn and their relevance to the study of disability and rehabilitation.

The abstract should not exceed 200 words.



### **Tables**

Tables and figures should be referred to in text as follows: figure 1, table 1, i.e. lower case. 'As seen in table [or figure] 1 ...' (not Tab., fig. or Fig).

Tables should be used only when they can present information more efficiently than running text. Care should be taken to avoid any arrangement that unduly increases the depth of a table, and the column heads should be made as brief as possible, using abbreviations liberally. Lines of data should not be numbered nor run numbers given unless those numbers are needed for reference in the text. Columns should not contain only one or two entries, nor should the same entry be repeated numerous times consecutively. Tables should be grouped at the end of the manuscript on uploaded separately to the main body of the text.

### **Figures and illustrations**

Figures must be uploaded separately and not embedded in the text. Avoid the use of colour and tints for purely aesthetic reasons. Figures should be produced as near to the finished size as possible. Files should be saved as one of the following formats: TIFF (tagged image file format), PostScript or EPS (encapsulated PostScript), and should contain all the necessary font information and the source file of the application (e.g. CorelDraw/Mac, CorelDraw/PC). All files must be 300 dpi or higher. Please note that it is in the author's interest to provide the highest quality figure format possible. Please do not hesitate to contact our Production Department if you have any queries.

### **Acknowledgments and Declaration of Interest sections**

Acknowledgments and Declaration of interest sections are different, and each has a specific purpose. The Acknowledgments section details special thanks, personal assistance, and dedications. Contributions from individuals who do not qualify for authorship should also be acknowledged here. Declarations of interest, however, refer to statements of financial support and/or statements of potential conflict of interest. Within this section also belongs disclosure of scientific writing assistance (use of an agency or agency/ freelance writer), grant support and numbers, and statements of employment, if applicable.

#### **Acknowledgments section**

Any acknowledgments authors wish to make should be included in a separate headed section at the end of the manuscript preceding any appendices, and before the references section. Please do not incorporate acknowledgments into notes or biographical notes.

#### **Declaration of Interest section**

All declarations of interest must be outlined under the subheading "Declaration of interest". If authors have no declarations of interest to report, this must be explicitly stated. The suggested, but not mandatory, wording in such an instance is: *The authors report no declarations of interest.* When submitting a paper via ScholarOne Manuscripts, the "Declaration of interest" field is compulsory (authors must either state the disclosures or report that there are none). If this section is left empty authors will not be able to progress with the submission.

## References

References should follow the Council of Science Editors (CSE) Citation & Sequence format. Only works actually cited in the text should be included in the references. Indicate in the text with Arabic numbers inside square brackets. Spelling in the reference list should follow the original. References should then be listed in numerical order at the end of the article. Further examples and information can be found in The CSE Manual for Authors, Editors, and Publishers, Seventh Edition. Periodical abbreviations should follow the style given by Index Medicus.

A description of employment patterns and day occupations of young adults  
with intellectual disability residing in Queensland

Sophia Davidson

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**Abstract**

The time of transition from school to post school for young adults with intellectual disability is challenging. The aim of this study was to describe the day occupations of young adults with intellectual disability residing in Queensland. We also sought to describe the number of young adults with intellectual disabilities currently in paid employment and the factors that impacted upon their employment or type of day occupations. *Method:* This study utilised previously collected data from the 2007 and

2009 ASK Transition project in Queensland to describe the day occupations of young adults who had left school (n=88) and the factors which impacted on these occupations. Variables of interest were categorised according to the International Classification of Functioning, Disability and Health (ICF) areas, and frequencies were compared across groups. *Results:* Overall functioning both in the areas of Activity and Impairments had the greatest impact on day occupations of young adults with intellectual disability. Those with poorer functioning were more likely to be in Post school options than employment or any other day occupations. *Conclusions:* Findings from this study highlight the importance of functioning in determining occupational outcomes for people with intellectual disability post school. This points to the need for service providers to target functioning as a means of improving participation outcomes for these individuals. Further research is needed to explore how environmental and personal factors mediate the relationship between activity and participation among young adults with intellectual disability.

**Keywords:** intellectual disability, day occupations, employment, young adults, Australia

## **Introduction**

In 2008, there were over half a million people with intellectual disability in Australia [1]. Intellectual disability is defined as originating before 18 years of age and is characterised by significant limitations in both intellectual functioning and adaptive behaviour as expressed in conceptual, social and practical adaptive skills [2]. People with intellectual disability experience difficulties in everyday tasks as reported in many studies [2, 3].

According to Erikson (1968), who described eight stages of psychosocial development, the stage of young adulthood spans stages five (identity versus role confusion) and six (intimacy versus isolation). Erikson proposed that during stage five the young adult develops an occupationally based identity, separate from their parents [4], and that a young adult is only able to move onto the next stage of development once their identity has been formed. Failure to accomplish these stages is seen as contributing to future mental health issues, identity and personality disorders, and behavioural issues [4].

For most young adults, establishing identity is accomplished by leaving home and living independently. However, for young adults with an intellectual disability achieving independence and identity formation is problematic [5]. Participation in employment and other day occupations provides important opportunities for identity formation to these young adults. For young adults with intellectual disability, who often lose peer contact following the completion of their schooling [6], work and day occupations provide an environment for establishing peer friendships and intimate relationships [7]. As people with intellectual disability are already predisposed to experiencing higher levels of undiagnosed mental illness, the opportunities to socialise with disabled and non-disabled peers, as achieved in day occupations and the workplace, is crucial.

Despite the importance of employment to young people with intellectual disability in Australia 65% of people with intellectual disabilities are unemployed, compared to 4.9% of the general population [8]. Research has reported that people with intellectual disabilities do not differ from the general population in their desire to participate in the work force [9]. For people with intellectual disability participation in employment



positively affects quality of life, promotes self-esteem and satisfaction with life, gives a sense of purpose, improves mental health, and enables social participation and inclusion. [10-14].

Research has highlighted that the economic and employment policies of a country have the greatest effect on the inclusion of people with intellectual disability in the workplace [5]. The Australian Government has stated that open employment is the most economically viable option for people with intellectual disabilities [15], as it reduces reliance on the government as individuals are not solely reliant on disability support pensions [15, 16]. However, despite the documented benefits and inclusive policies people with intellectual disabilities still remain under represented in employment and meaningful day occupations. Further examination of the specific factors that impact on the employment of young adults with intellectual disability in Australia is necessary.

The purpose of this study was to describe the day occupations of young adults with intellectual disability residing in Queensland. We also sought to describe the number of young adults with intellectual disabilities currently in paid employment and the factors that impacted upon their employment or type of day occupations. The International Classification of Functioning Disability and Health (see Figure 1) was used as the theoretical framework for this study and we sought to examine how the areas of Body Structures and Function (Impairment factors), Activity factors (restrictions in functioning), as well as Contextual factors including Personal and Environmental factors related to the participation on young adults with intellectual disability in day occupations [17].

## **Methods**

### *Background methodology*

The ASK cohort was originally recruited from Queensland support education centres and surveyed in 2007 (n=596) and 2009 (n=389). Of the ASK cohort of 2009 consent for further contact was received from (n=255) families. (See Figure 2 Flow chart) At both time points parents and guardians were requested to complete a questionnaire

relevant to their young adults with intellectual disability. From the 2007 survey demographic information about the family and the functioning ability of the young adult were obtained. Information used from the 2009 surveys included the young person's health, family life, the transition stage, accommodation, social relationships and activities, everyday functioning and measures of parental mental and physical health. In 2009, 149 families of young adults with intellectual disabilities aged between 17 and 24 took part in the ASK Transition Project surveys. The current analysis was restricted to those young adults who had left school in 2009 resulting in a sample of 88 (59% of 149 respondents). All data used in this study, except where stated, was obtained from the 2009 questionnaire.

#### *Data Collection/Materials*

The International Classification of Functioning Disability and Health provided the conceptual framework for this study [17]. Factors likely to impact on day activity outcomes were classified into Impairment factors, Activity factors, Contextual factors both Personal and Environmental as outlined by the ICF [17]. The young adults' *Impairment factors* were captured by a numerical count of annual GP visits, episodes of illness and hospital stays in last 12 months, and number of co-morbid medical conditions. Co-morbid medical conditions included; Epilepsy, Heart condition, Psychiatric condition, Diabetes, Vision problems, Hearing problems, Thyroid problems, Constipation, Reflex oesophagitis and Aspiration. Behaviour of the young adult was measured using the Developmental Behaviour Checklist 24-item Short version (DBC P-24) [18].

*Activity factors* were measured using a modified version of the Barthel Index [19] which examined functioning in the areas of feeding, bathing, grooming, dressing, bowels, bladder, toilet use, mobility and stairs, and was obtained from the 2007 questionnaire. Everyday functioning was further measured in relation to the young adults' ability to tell the time, handle money, deal with social events, learn new skills, communicate and catch public transport.

*Contextual factors* in relation to *personal factors* analysed included age group (17-19 years, 20-22 years, 23-31 years), gender and years since leaving school. *Environmental factors* included informal assistance needs (measured by the Family Resources Scale (FRS)) [20], parental availability of time (measured by the FRS) [20]), place of



residence, type of school attended by young adult, and self-rated family financial status. Parental physical and mental health status was measured by SF-12 version 2 Health survey [21], and the presence of negative emotional states of Depression, Anxiety and Stress was measured by the Depression, Anxiety and Stress Scale (DASS) [22]. Parental demographic information was collected in 2007 and included gender, highest schooling level completed, highest qualification completed, current employment status, occupation, and relationship status. Parents' level of satisfaction with family quality of life was measured by the Beach Centre Family Quality of Life Scale [23].

*Participation in day occupations* of the young adults with intellectual disability, the outcome of this study, was measured in relation to type of day occupations, open or sheltered employment, training, post-school options, or no day activities. Employment was further analysed in relation to type and hours. In open employment employees with intellectual disability receive assistance as required through co-workers and other natural supports and are generally paid competitive wages. Sheltered employment settings referred to factory or manual labour jobs where employees were paid by their productivity rate through a Disability Enterprises Scheme such as Endeavour, Queensland's leading employment agency for people with disabilities. Employees do not receive a competitive salary. Training or Tafe, included life and social skills training and employment preparation. Those in Post School Options were young adults who did not participate in any training or employment occupations, but were involved in organised leisure activities, outings and daytime activities through a day centre or similar. Those in no day occupations were young adults whose parents reported that they were not ready or unwilling to work, had recently left their previous day occupation, were awaiting job agency support or did not wish to participate in any occupations for another reason.

#### *Data Coding and Analysis*

Participants in this study were divided into three age groups for analysis: those experiencing early transition aged between 17 and 19, and those experiencing later transition aged between 20 to 22 and 23 to 31. Data for analysis was cleaned, coded and categorised in Filemaker Pro and then exported to STATA version 10 for statistical

analyses [24]. Descriptive statistics were used to explore the data in relation to frequencies, and measures of central tendency and variability. Chi-square statistics were used to analyse the relationship between day occupations and categorical factors. Oneway ANOVA of day occupations was conducted with continuous variables such as behaviour as measured by the DBC P-24, modified Barthel Index, everyday functioning questions, communication ability, DASS, SF-12 v2, the Beach Family Quality of Life measure and FRS. Bonferroni post hoc comparisons of the five groups were used to examine differences between day activity groups. Statistical significance for all tests was set *a priori* at  $p < 0.05$ .

## Results

The characteristics of the 88 participants in the 2009 cohort are described in Table 1. Most young adults were aged 20 to 22 years, the youngest was 17 and the eldest 24, and there were 41 females and 47 males.

### *Impairment factors*

Impairment factors included problem behaviour, annual GP visits, episodes of illness, hospital visits and number of co-morbid medical conditions. The frequencies of the young adults' impairment factors across day activity groups are shown in Table 1. The Impairment factors of the young adults did not differ significantly across day occupation groups, however young adults in Post School Options had a higher number of annual GP visits, more episodes of illness throughout the year and a higher number of co-morbidities than young adults in all other day occupation groups. Behaviour of the young adults as measured by the DBC P-24, did not differ among the day occupation groups ( $F(4,83) = 0.49, p = 0.743$ ), however young adults in Open ( $M = 14, SD = 9.3$ ) or Sheltered employment ( $M = 15, SD = 9.0$ ) had lower mean total problem behaviour scores than young adults in all other day occupation groups.

### *Activity factors*

The frequencies, descriptors and one-way ANOVA for Activity factors are presented in Table 2. One-way ANOVA was used to test for differences in every day functioning across the day occupation groups which differed significantly in relation to all measures (see Table 2). Functioning was measured by parental responses to the questions regarding the ability of their young adult to complete everyday functional activities such as tell the time, use money, communicate and conduct their activities of daily living

(dressing, bathing, grooming, toilet use, mobility etc.). Everyday functioning differed significantly across groups in relation to the young adults ability to tell the time  $F(4,75) = 2.90$ ,  $p=0.027$ , handle money  $F(4,83) = 5.47$ ,  $p=0.001$ , learn new skills  $F(4,77) = 5.26$ ,  $p=0.001$ , deal with social events  $F(4,74) = 3.63$ ,  $p=0.009$ , and ability to use public transport  $F(4,78) = 7.75$ ,  $p=0.000$ . Communication skills also differed significantly across groups,  $F(4,82) = 5.75$ ,  $p=0.000$ . Functioning as measured by a modified version of the Barthel Index differed significantly across day occupation groups,  $F(4,83) = 11.53$ ,  $p=0.000$ . Overall those in post school options had poorer functioning than those in other day occupation groups (see Table 2).

#### *Participation in day occupations*

Almost half ( $n=40$ , 45%) of the young adults were in paid employment. Of these young adults 28% ( $n=11$ ) were in manual or factory labourer jobs, 28% ( $n=11$ ) were employed by Endeavour, a supported employment provider, 25% ( $n=10$ ) were employed in the hospitality industry as kitchen hands, waiters/waitresses and cleaners, 8% ( $n=3$ ) were employed as cashiers and shop assistants and one was employed in office or clerical work. The remaining 25% ( $n=10$ ) were employed in jobs which did not fall into any of these categories such as helping out in a childcare centre. More than half of the families 56% ( $n=23$ ) recorded their young adults hours spent in employment per week. Of these 3 were only working up to 5 hours per week, 5 were working 6-10 hours, 6 were working 11-15 hours a week, 3 were working 16-20 hours a week and 5 were working over 20 hours per week.

#### *Person factors*

One quarter ( $n=23$ ) of the young adults were aged between 17 and 19 years, two thirds ( $n=61$ ) were aged between 20 and 22 years, and 4 were aged between 23 and 31 years. The cause of disability of the young adults differed, 19 of the young adults had a diagnosis of Down syndrome, 45 were diagnosed with intellectual disability resulting from Autism Spectrum Disorder, chromosomal disorder, birth trauma, William's syndrome and Prader Willi syndrome. The remaining 24 had an intellectual disability of an unknown cause. In 94% of the families, young adults were still residing in the family home, 4% lived with other relatives outside of the family home, and 2% were in group homes or community residential units. Slightly more young adults attended a Special education school ( $n=48$ ) than a Special education unit within a mainstream



school (n=40) ( $X^2=18.97$ ,  $p = .001$ ). Young adults time since leaving school was categorised into three groups, less than one year (n= 33), one to two years (n=29) and more than two years (n=22).

#### *Environmental factors*

Categorical environmental factors are presented in Table 1. More than 85% of primary carers were female (n=77) and 95% of carers were a parent of the young adult. In most families parents' highest education level was year 10 or equivalent (n=37), followed by year 12 or equivalent (n=34), no formal qualification (n=31), and then attainment of a Certificate (n=23). Forty six mothers reported working within the two lowest levels as rated by Australian New Zealand Standard Classification of Occupations [25] as community or personal service workers. Primary carers or parents of the young adult were mostly employed part-time (n=38) or completing home duties (n=24). More than half of all carers had a current partner (n=68) and those with current partners were more likely to have young adults in post school options ( $X^2=10.46$ ,  $p=0.033$ ). Half of the partners of primary carers were in full time employment (n=45). More than half of the families reported that they were poor or just getting by financially. Self-rated financial status of families did differ across day occupation groups ( $X^2=17.39$ ,  $p=0.361$ ).

Continuous environmental factors are presented in Table 2. Parental physical and emotional health was measured with a variety of standardised assessments. Although there was no significance difference between day occupation groups, ( $F(4,81) = 0.09$ ,  $p=0.985$ ), parental or primary caregiver mental health, as measured by the DASS, demonstrated that across all groups parents were on average experiencing mild to moderate in depression, anxiety and stress levels. Mental health was also measured using the SF-12 health survey and although there was no significance between groups, ( $F(4,81) = 0.70$ ,  $p=0.595$ ), on average the Mental Health Component (MCS) scores of all parents ( $M= 34.8$ ,  $SD=6.3$ ) fell far below the Australian female norm of 51.4[26].

Family quality of life as measured by the Beach Centre Family Quality of Life measure did not differ between day occupation groups, ( $F(4,82)=1.57$ ,  $p=0.190$ ), however quality of life scores of families whose young adult was in Open ( $M=94$ ,  $SD=11.7$ ) or Sheltered employment ( $M=97$ ,  $SD=14.8$ ) was rated slightly higher than families with a young adult in other day occupations.

Parental Availability of Time varied between groups,  $F(4,80)=2.66$ ,  $p=0.038$ , with parents of young adults in Open ( $M=30$ ,  $SD=6.7$ ) or Sheltered ( $M=29$ ,  $SD=9.3$ ) employment reporting more availability of time in comparison to other groups. Perceived informal assistance needs were also measured but did not differ across groups,  $F(4,81)=0.55$ ,  $p=0.702$ ).

### **Discussion**

In this study we aimed to describe the day occupations of young adults with intellectual disability in Queensland and factors that impact on these occupations. Almost half of the young adults were in employment. Of those not in employment more than half were attending post school options, and nearly equal number were in training ( $n=11$ ) or involved in no day occupations ( $n=10$ ). Therefore, over half of the young adults were unemployed. This findings is reflective of research undertaken by the Australian Bureau of Statistics which reported that 65% of people with intellectual disability are unemployed compared to 4.9% of the non-disabled community [8, 27]. Research has also reported that intellectually disabled people who are employed are often working for below minimum wages and at reduced hours [11, 28, 29]. Given that participation in employment also has many social, financial and quality of life benefits [12] for people with intellectual disability, and the finding that including people with intellectual disabilities in open employment is more economical than alternatives to employment such as adult day service programs [15], service providers must continue to focus their efforts on improving the employment participation of people with intellectual disability.

In applying the ICF to our study, day occupations were explored with the understanding that participation is affected by the capacity of the individual, and that both intrinsic and extrinsic factors act as barriers or facilitators to participation [17]. Importantly this study found that impairment factors such as behaviour and health issues and activity factors such as functioning had the greatest impact on day occupations. Young adults in Post School Options were reported to have poorer functioning in everyday activities than peers in all other day occupations. This finding parallels previous research which suggests that young adults with intellectual disability in training or employment settings have higher functioning levels than their unemployed peers [7, 11, 14, 30]. These

findings highlight the need for occupational therapists, who are specifically trained in maximising functioning through training and environmental modification, to use their knowledge to maximise the functioning and subsequently improve the employment participation of young adults with intellectual disabilities.

Our finding that young adults in Post School Options (organised leisure activities) also had significantly lower functioning in instrumental activities of daily living than young adults in all other day occupation groups is consistent with previous research. Higher functioning among young adults with intellectual disability has been linked to greater social, community and employment participation rates compared to young adults with poorer functioning [31, 32]. Previous research has highlighted the effectiveness of interventions targeted at improving the functional skills of young adults with intellectual disability and the positive impact these interventions have on participation outcomes [5, 33]. Improvements in community skills leads to increased autonomy and independence for individuals with intellectual disability enabling them to increase their control over their life choices and daily occupations [31, 33]. Collectively these findings highlight the important role that occupational therapists can play in increasing the everyday independence of young adults with intellectual disability.

Impairment factors such as annual GP visits, episodes of illness and number of co-morbidities were further found to negatively impact on day occupations of the young adults. Young adults with poorer overall health were more likely to be attending Post school options rather than participating in employment or training. Young adults with intellectual disability often have multiple co-morbid medical conditions which further impact their ability to participate as their typically developing peers [34]. Despite improvements in the overall health of young people with intellectual disability [34] impairments in body structures and functions still continue to impact on their ability to participate in employment.

In addition, young adults with poor behaviour were less likely to be involved in employment or training activities than their peers with fewer behavioural problems. The presence of behavioural problems (antisocial, disruptive, self-absorbed behaviours) is reportedly two to three times more common in people with intellectual disability than the general population [18, 35]. Further the presence of challenging behaviours seriously limits work outcomes [5]. This indicates the need for occupational therapists,



health professionals and disability support services to focus on managing challenging behaviours as a means of increasing the participation of young adults with intellectual disability [36].

Our finding that young adults with better communication skills had higher participation in open employment, sheltered employment and training activities than young adults in Post school options or no day occupations is in accordance with previous research. Many authors have suggested that amongst the population of people with speech, language and communication difficulties unemployment rates are higher than their peers without communication difficulties. People with communication difficulties are also eight times more likely to be unemployed, to be in a lower socio-economic groups, receive lower wages and be at risk for poor mental health [37-39]. Further, co-workers avoid interacting with people with communication difficulties due to the extra effort and strain involved [39]. For the population of young adults with intellectual disabilities this contributes to further social isolation. Occupational therapists, as part of a multi-disciplinary team are able to work with Speech pathologists to improve the communication ability and social skills of people with intellectual disability through providing alternative means of communication such as augmentative communication devices or communication books.

More than half of the families surveyed (n=50) reported their financial status as just getting by or poor. This is consistent with previous literature which reported higher levels of economic disadvantage amongst families caring for a young adult with an intellectual disability [3, 28]. This reinforces the need for health professionals working with families of young adults with intellectual disability to have adequate knowledge of the disability system and direct families towards possible sources of funding to support their young adult.

Our finding that carers who were mostly mothers, reported mild to moderate levels of depression, anxiety and stress on the DASS and had significantly lower mental health scores on the SF-12 v2 than the Australian female norm of 51.4 [40] are consistent with previous research [41-43]. These findings are of particular concern and highlight the burden carried by these carers. Further some authors have suggested that parental

mental health outcomes affect the day occupations and participation of the young adults with intellectual disability [6]. Therefore as health professionals who have regular contact with these carers it is our role to provide support and make recommendations for further assistance.

In interpreting the findings from this study the following limitations must be acknowledged. It is likely that the sample for this study may not represent the population of young adults with intellectual disability living in Queensland, but reflects those who provided follow-up consent to the ASK study. The length of the questionnaire may have contributed to respondent fatigue and there may also be some recall error associated with retrospective proxy report of parents. Further, the data analysed in this research reflects the views of parents, not those of young adults with intellectual disability themselves.

The overall findings of this study highlight the significant influence of functioning on day occupations of young adults with intellectual disability. Further research is now required to explore the role that environmental and personal factors have in mediating this relationship. Understanding these relationships will highlight those areas which should be targeted by interventions. This would ultimately improve the participation of young adults with intellectual disability in meaningful employment and day occupations.



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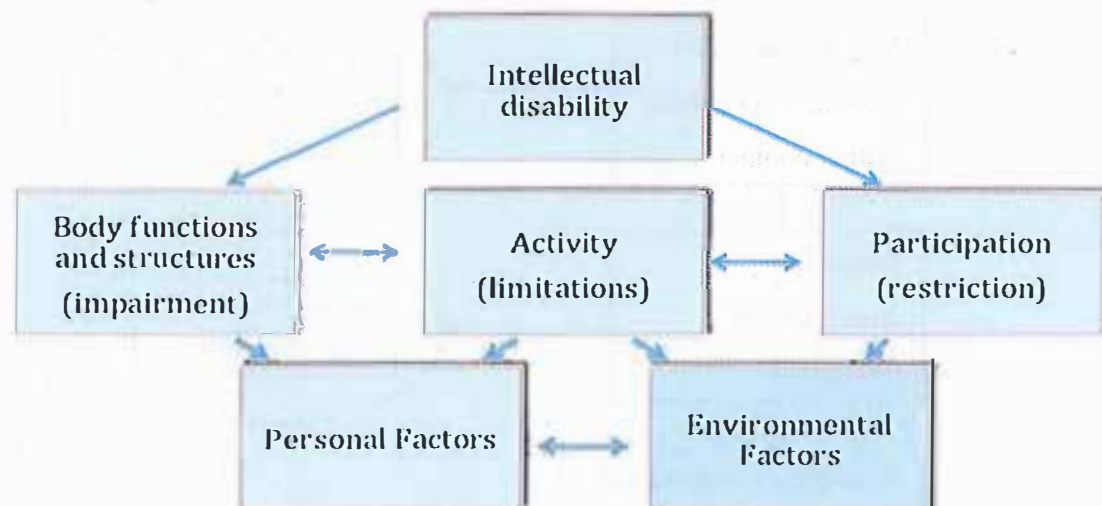
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**APPENDICES**



Figure 1: ICF Diagram

[1]



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Figure 2: Flow Chart

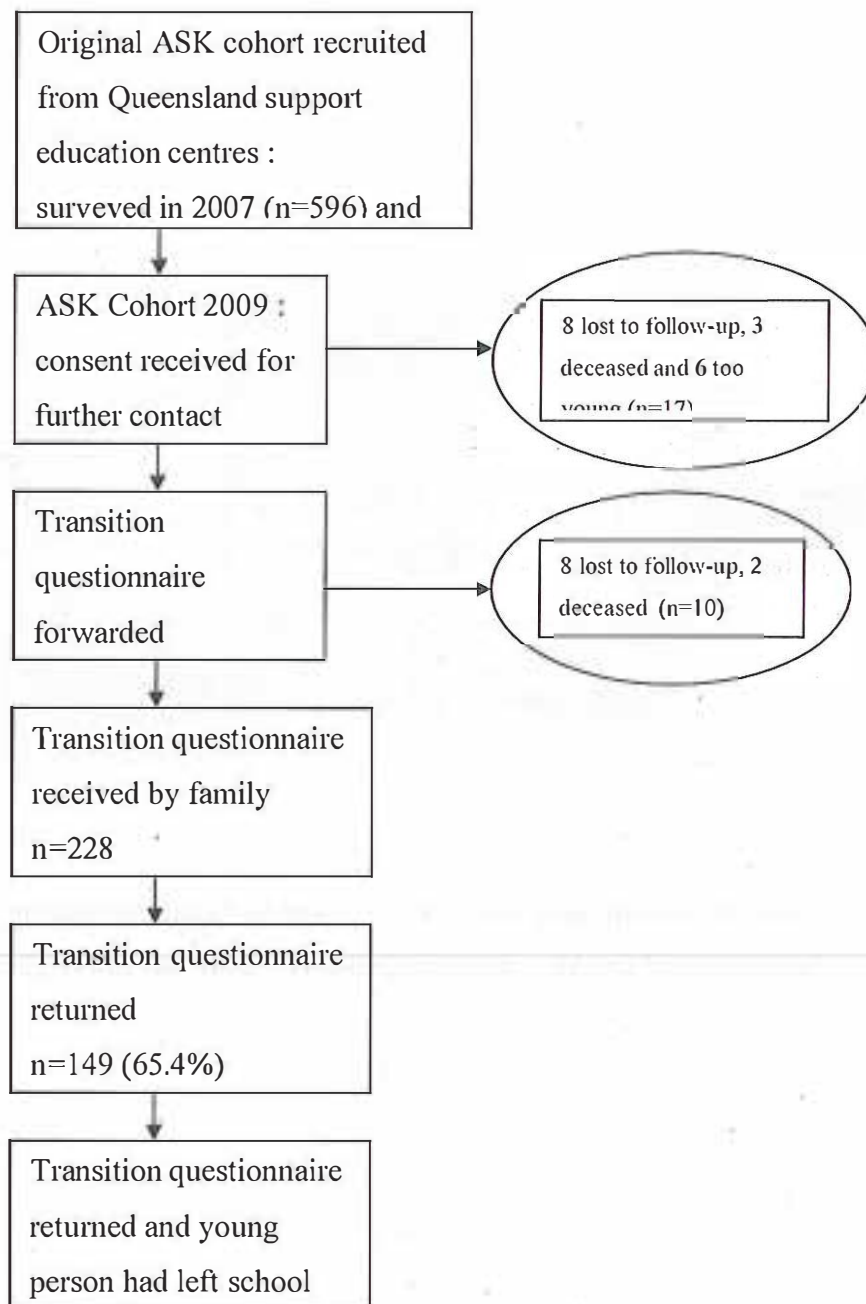


Table 1 Characteristics of Participants

	Overall cohort (n=88)		Open (n=24)		Training (n=11)		Sheltered (n=15)		PSO (n=28)		No day occupations (n=10)		Pearson $\chi^2$ test	
	Freq	%	Freq	%	Freq	%	Freq	%	Freq	%	Freq	%	$\chi^2$	Sig (*) if $p < .05$
Person factors														
Gender														
Female	41	47	11	27	9	22	5	12	12	29	4	10	6.88	.142
Male	47	53	13	28	2	4	10	21	16	34	6	13		
Age group														
17-19 year olds	23	26	7	30	6	26	1	4	5	22	4	17	12.50	.130
20-22 year olds	61	69	15	24	5	8	14	22	21	34	6	10		
23-31 year olds	4	5	2	50	0	0	0	0	2	50	0	0		
Place of residence														
Family home	70	94	22	31	9	13	15	21	26	37	7	10	27.02	.08
Group home or Community Residential Unit	2	2	0	0	0	0	0	0	0	0	2	50		
Unit or house with other relatives	3	4	1	33	1	33	0	0	0	0	1	33		
Type of school attended														
Special education unit within Mainstream school	40	45	15	38	3	8	9	22	5	12	8	20	18.97	.001*
Special Education school	48	55	9	19	8	16	6	13	23	48	2	4		
Years since leaving school														
< 1 year	33	39	10	30	4	12	5	15	9	27	5	15	2.92	.939
1-2 years	29	35	7	24	4	14	4	14	10	34	4	14		
> 2 years	22	26	6	27	2	10	5	23	8	36	1	5		
Cause of disability														
Down syndrome	19	22	5	26	1	5	5	26	7	37	1	5	10.26	.594
Other specified	45	51	10	22	8	18	6	13	13	29	8	18		
Unknown cause	24	29	9	38	2	8	4	17	8	33	1	4		
Impairment factors														
Annual GP visits														
0-1	12	14	4	33	0	0	1	8	2	17	5	42	25.91	.169
2	11	13	4	36	0	0	3	27	3	27	1	9		
3	12	14	4	33	3	25	2	17	3	25	0	0		



Postgraduate degree	5	6	2	40	0	0	1	20	2	40	0	0	28.94	.416
Graduate diploma/cert	6	7	2	33	0	0	2	33	2	33	0	0		
Bachelor degree	8	9	1	13	0	0	0	0	5	63	2	25		
Advanced diploma/diploma	5	6	0	0	0	0	0	0	4	80	1	20		
Certificate	23	26	7	30	4	17	7	30	4	17	1	4		
None of the above	31	35	10	32	4	13	5	16	7	23	5	16		
Other	10	11	2	25	2	25	0	0	3	30	1	10		
Mothers occupation														
1 - Managers	3	5	1	33	0	0	0	0	2	67	0	0	7.74	.459
2- Professionals	16	25	5	31	0	0	2	13	8	50	1	6		
/technicians/ trades workers														
3- Community/ Personal Service workers	46	71	12	26	6	13	10	22	13	28	5	11		
Father occupation														
1 - Managers	0	0	0	0	0	0	0	0	0	0	0	0	0.83	.660
2- Professionals/ technicians/ trades workers	3	60	0	0	1	33	0	33	1	33	1	33		
3- Community/ Personal Service workers	2	40	0	0	0	0	0	0	1	50	1	50		
Carer's Current employment status														
Employed full time	13	15	1	8	1	8	2	15	9	69	0	0	37.76	.103
Employed part time or casual	38	43	11	29	2	5	8	21	13	34	4	11		
Home duties	24	27	7	29	5	21	3	13	4	17	5	19		
Unemployed	1	1	0	0	0	0	1	100	0	0	0	0		
Full-time student	3	3	1	33	2	67	0	0	0	0	0	0		
Retired	4	5	2	50	0	0	0	0	1	25	1	25		
Permanently ill/unable to work	3	3	1	33	1	3	0	0	1	33	0	0		
Unknown	2	2	1	50	0	0	1	50	0	0	0	0		
Current partner														
Yes	68	77	18	26	5	7	11	16	26	38	8	12	10.46	.033*
No	20	23	6	30	6	30	4	20	2	10	2	10		
Carer's partner's employment status														
Employed full time	45	51	13	29	3	7	9	20	17	38	3	7	34.67	.073

Employed part time or casual	7	8	3	43	0	0	0	0	2	29	2	29		
Home duties	4	5	0	0	0	0	0	0	2	50	2	50		
Unemployed	1	1	0	0	1	100	0	0	0	0	0	0		
Full-time student	0	0	0	0	0	0	0	0	0	0	0	0		
Retired	4	5	1	25	1	25	0	0	2	50	0	0		
Permanently ill/unable to work	7	8	1	14	0	0	2	29	3	43	1	14		
Self-rated financial status														
Just getting by or poor	50	58	10	20	7	14	6	12	19	38	8	16	17.39	.361
Comfortable or better	36	42	14	39	3	8	8	22	9	25	2	6		



Table 2 Analysis of continuous variables and day occupations

Variables of Interest

	Day occupation						P value Sig (*) if < .05	Df between	Df within									
	Open (n=24)		Training (n=11)		Sheltered (n=15)					PSO (n=28)		No day occupation (n=10)						
	Freq	Mean (SD)	Min- Max	Freq	Mean (SD)	Min- Max	Freq	Mean (SD)	Min Max	Freq	Mean (SD)	Min Max	Freq	Mean (SD)	Min Max			
Impairment factors																		
Behaviour DBC P24 <sup>a</sup>	24	14 (9.3)	2-42	11	17 (7.7)	9-32	15	15 (9.0)	3-37	28	17 (7.7)	3-31	10	17 (11.4)	6-39	.743	4	83
Activity factors																		
Functioning <sup>b</sup>																		
Time	23	2 (1.3)	1-4	11	3 (1.3)	1-4	14	3 (1.2)	1-4	23	2 (1.1)	1-4	9	3 (1.3)	1-4	.027*	4	75
Money	24	3 (1.2)	1-5	11	2 (.9)	1-4	15	3 (1.5)	1-5	28	2 (1.1)	1-5	10	3 (1.7)	1-5	.001*	4	83
New Skills	24	3 (.9)	1-4	10	3 (.8)	1-4	14	3 (1.0)	1-5	25	2 (1.0)	1-4	9	3 (1.0)	1-4	.009*	4	77
Social Events	24	3 (1.5)	1-5	11	3 (1.6)	1-5	13	3 (1.7)	1-5	23	1 (1.0)	1-4	8	3 (1.4)	1-4	.009*	4	74
Public Transport	22	3 (1.7)	1-6	11	3 (1.9)	1-6	14	3 (2.1)	1-6	27	1 (.7)	1-4	9	4 (2.1)	1-6	.000*	4	78
Communication <sup>c</sup>	23	1 (0)	1-1	11	1 (.9)	1-4	15	1 (.3)	1-2	28	2 (1.0)	1-4	10	2 (1.0)	1-4	.000*	4	82
Modified Barthel Index <sup>d</sup>	24	25 (2.0)	21-27	11	24 (3.8)	15-27	15	25 (3.3)	14-27	28	20 (4.6)	9- 27	10	25 (2.0)	21- 27	.000*	4	83
Environmental factors																		
Parent Emotional State																		
Depression	24	14 (14.9)	2-44	11	14 (12.0)	2-40	15	13 (12.5)	0-44	27	14 (9.2)	2-44	9	14 (8)	2-26	.996	4	81
Anxiety	24	8 (11.5)	0-40	11	7 (7.3)	0-24	15	7 (7.4)	0-24	27	7 (7.9)	0-34	9	6 (4.7)	0-16	.973	4	81
Stress	24	15 (13.0)	0-42	11	18 (11.9)	0-36	15	13 (11.2)	0-34	27	15 (10.6)	0-36	9	15 (7.4)	2-22	.912	4	81
Total DASS score <sup>e</sup>	24	37 (37.2)	2-122	11	39 (28.9)	2-92	15	33 (30.0)	0-102	27	35 (24.3)	2-98	9	35 (16.9)	6-60	.985	4	81
Parent SF-12 PCS <sup>f</sup>	24	49 (10.1)	31-65	11	44 (11.2)	28-58	15	46 (10.1)	31-62	27	50 (9.8)	27- 64	9	41 (7.7)	30- 53	.146	4	81
Parent SF-12 MCS	24	34 (6.2)	26-48	11	34 (5.8)	20-43	15	37 (5.6)	27-44	27	34 (6.1)	18- 44	9	36 (8.7)	22- 52	.595	4	81

Beach Family quality of life <sup>g</sup>	24	94 (11.7)	74- 122	10	86 (19.0)	56- 118	15	97 (14.8)	79- 122	28	89 (14.9)	61- 119	10	86 (16.0)	56- 103	.190	4	82
Parental Availability of Time <sup>h</sup>	24	30 (6.7)	16-41	11	25 (7.2)	13-40	15	29 (9.3)	13-41	27	24 (6.7)	10- 36	8	26 (7.9)	17- 40	.038*	4	80
Informal Assistance Needs <sup>i</sup>	24	21 (12.3)	0-37	11	22 (9.1)	8-35	15	24 (9.6)	9-43	28	24 (8.3)	6-44	8	21 (7.4)	12- 35	.702	4	81

<sup>a</sup> Developmental Behaviour Checklist, higher score = higher total problem behaviour

<sup>b</sup> Functioning, Time-Public Transport, higher score= better functioning

<sup>c</sup> Communication, lower score= better communication

<sup>d</sup> Modified Barthel Index, higher score= better functioning

<sup>e</sup> DASS scores, higher score = poorer mental health

<sup>f</sup> SF-12, PCS physical health component, MCS mental health component, higher score=better functioning

<sup>g</sup> Family quality of life, high score= higher quality of life

<sup>h</sup> Parental availability of time, higher score=more time available

<sup>i</sup> Informal assistance needs, higher score= more assistance required

*Disability and Rehabilitation guidelines for authors* not part of Research Report appendices in this version of the thesis.