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School to post-school transition programs for young adults with intellectual disabilities: A systematic review, and; the meaning of well-being from the perspective of young adults with Down syndrome

Melissa Scott
Edith Cowan University

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School to post-school transition programs for young adults with intellectual disabilities: A systematic review

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The meaning of well-being from the perspective of young adults with Down syndrome

Melissa Scott

Bachelor of Science (Occupational Therapy) (Honours)

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Melissa Scott

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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Melissa Scott

School to post-school transition programs for young adults with intellectual disability: A systematic review

Abstract

Objective: 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: All eight articles 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.

Melissa Scott
Dr Sonya Girdler
October, 2011

The meaning of well-being from the perspective of young adults with Down syndrome

MELISSA T.SCOTT & SONYA J.GIRDLER

Department of Occupational Therapy, School of Exercise, Biomedical and Health Science, Edith Cowan University, Perth, Australia and [2]Telethon Institute for Child Health Research, University of Western Australia, Perth, Australia

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.
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Keywords: Intellectual disability, transition programs, post-school, participation, young adults

Introduction

Intellectual disability is commonly defined as significant cognitive impairment with deficits in adaptive behaviour evident during the developmental period [1]. Intellectual disability accounts for 3% of the Australian population [2] and occurs approximately in 8.3 per 1000 live births [3]. Nationally this condition places significant demands on families, health and education systems and disability services [4]. Despite this, research in this field is limited particularly in relation to research examining the transition period from school to post-school for young adults with intellectual disability [5].

The transition from school to post-school is a challenging and critical life stage for any young adult [6]. Young adulthood is a period whereby major social roles are developed, independence is achieved and identities are established [7]. At this time typically developing young adults commonly attend university, begin apprenticeships or enter the workforce [8]. However, for young adults with intellectual disability the transition period occurs for a longer duration than their non-disabled peers and they encounter many challenges in acquiring normative adult social roles [9, 10]. The International Classification of Functioning, Disability and Health (ICF), has defined normative adult social roles in the domain of participation. This encompasses involvement in the major life areas of; education, employment, self-sufficiency, and community and social life [9].

For young adults with intellectual disability transition programs or services are important in supporting the transition into such adult social roles [11]. The intended outcomes of transition programs are to provide opportunities for postsecondary education, employment and recreational activities [12]. Although such transition programs exist, current models of service provision have been criticised as having a number of key problems [5]. Fundamentally these programs have been described as limited by their lack of focus on holistic and life goal-orientated services [11]. Families have described the limitations of current models of service delivery as including; a lack of information and support regarding available services and transition plans, lack of communication and collaboration between families and services, poor person-centred planning, and as presenting barriers to accessing services [5].

In Australia, the government has attempted to support transition programs through legislation and policy development [13]. However, despite these efforts, current models of service provision continue to result in poor post-school outcomes for young adults with intellectual disability [14, 15]. Consequently many of these young adults have limited opportunities for community participation, age-appropriate social activities, vocational training and development of functional life skills [12, 16].

In order to improve transition outcomes for young adults with intellectual disability there is need for more effective models of service delivery, implemented with greater consistency [11]. It is essential that such models include good practice principles that underlie transition planning [5].Therefore, the objective of this systematic review was to describe the effectiveness of school to post-school transition programs and their impact on community participation, friendships and quality of life for young adults with intellectual disability.

Methods

The review was conducted using the standards and techniques of systematic reviews [17]. Electronic searches of CINAHL Plus with Full Text, MEDLINE, ERIC, PsychINFO, SPORTDiscus with Full Text were undertaken from 1990 and Web of Science from 1985 to June 2011. The main search terms were; Down syndrome or intellectual disability, transition programs or services, community or day activities, participation, and young adults. A librarian assisted with the truncation, expansion and adjustment of all search terms to match the databases. No language restrictions were used, however searches were limited to published articles. A further manual search of reference lists of all relevant retrieved articles was conducted to identify additional significant papers.

A *priori* criteria for inclusion of studies was initially applied to the retrieved abstracts, however if insufficient information was provided, full text articles were then reviewed. Studies were included if the interventions were described as; transition programs or services or postsecondary education programs, aimed at supporting the transition of young adults with intellectual disability from school to post-school. The mode, length and frequency of the transition programs or service providers were not limited. Participants of included studies were restricted to adolescents, youth and young adults with intellectual disability aged 15-25 years, who were the sole or majority of participants. Outcomes of interest included: community participation, friendships and quality of life.

Assessment of methodological quality

Two reviewers independently assessed the quality of each study using the Kmet tool for qualitative and quantitative studies [18]. This tool comprises of a checklist of 10 questions for qualitative studies and 14 questions for quantitative studies and a scoring system is used to obtain an overall score for quality of the study. Quality scores were developed according to the guidelines and instruction manual [18]. Scores were represented as percentages with the strength of the evidence being categorised as, strong (> 80%), good (70-80%), adequate (50-70%) or limited (< 50%). Any inconsistencies in quality assessment were resolved through discussion.

Data extraction

Two reviewers independently extracted data from potential studies using the methods described in section 7 of the *Cochrane Handbook for Systematic Reviews of Interventions* [10]. Data extracted included: study design, methods of participant selection, sample size, study objectives, interventions, main findings, and conclusions. Once data extraction was complete the level of evidence was determined based on the National Health and Medical Research Council [19].

Data synthesis and analysis

Due to non-traditional methods and analyses in the majority of the studies and the small number of protocols accounted for, a meta-analysis was not possible. Alternatively, a systematic review was conducted in order to collate the extracted data and present a summary of the studies' results, quality and provide an assessment of methodological issues.

Results

Electronic databases retrieved 170 articles from CINAHL, 6 from MEDLINE, 35 from ERIC, 92 from PsychINFO, 143 from SPORTDiscus and 225 from Web of Science, a total of 671 potential articles after adjusting for duplicates, as seen in figure 1. Titles and abstracts were then reviewed according to the stated inclusion criteria, resulting in 649 articles deemed irrelevant. The 22 remaining full text articles were then reviewed for inclusion.

Eight articles met the inclusion criteria with a total count of 573 participants. Of the eight articles, four reported interventions described as; school to post-school transition-focused programs and supports [12, 16, 20, 21]. Three articles [5, 22, 23] reported perceptions and experiences of parents and carers of young adults with intellectual disability. Of the eight included studies, four were qualitative, two quantitative in nature and two utilised a mixed methods approach. Study designs included; interviews, case studies, focus groups, surveys, questionnaires and one longitudinal study with pre/post comparison of participant interviews [24].

Quality assessment of studies

A tabulated ‘Description of included studies’ displays the; first author, year of publication and country, study design, intervention, data collection and analysis techniques, results, summary of findings and themes and methodological quality of the included studies. The methodological quality of the eight articles ranged from adequate to strong. As seen in table 1.

Parental and carer perspectives and experiences were described in three of the studies, with the quality of the evidence rated from adequate to strong [5, 22, 23]. Each of these studies reported parents’ perceptions of the impact of the transition process from school to post-school on the young adult and the perceived barriers and facilitators to the transition process. Four of the studies examined transition-focused programs aimed at community participation, social inclusion, employment/vocational training and post-school adult services. The methodological quality of these studies was also rated from adequate to strong [12, 16, 20, 21]. One longitudinal study, rated as good, described the attrition from services during the transition process into adulthood for the young adults with intellectual disability [24].

Methodological shortcomings were evident in both qualitative and quantitative studies. Two quantitative studies did not adequately describe their analytic methods or report their results in sufficient detail [12, 23]. Both studies reported using the data management package SPSS, however, neither reported on their statistical analysis. Consequently, adequate interpretations of the data by the reader could not be made, contributing to lower quality scores. Two qualitative studies described small sample sizes [20, 22]. Due to the multidimensional nature of the transition experience for young adults with intellectual disability, it is likely that larger sample sizes would be required to reach saturation [25]. Further shortcomings of qualitative studies included a lack of a connection to theoretical frameworks or a wider body of knowledge, and in all but two cases failure to address the key components of trustworthiness [16, 22].

Interventions

This review identified research examining three transition programs delivered in a post-school environment [12, 20, 21]. All three programs were delivered on university campuses during the young adults’ final years of high school. These programs reported positive transition outcomes including; social inclusion with peers, employment, access to vocational and living skills training, and participation within age-appropriate environments [12, 20, 21]. A further study specifically examined the impact of a transition focused school-based program on community participation and social activities of young adults with intellectual disability [16]. Outcomes of this program included participation of all participants in at least one weekly community activity. Due to the nature of this research, no comparison groups were available.

Main findings and themes

Barriers and facilitators to the transition process

Across included studies parents and carers identified a range of barriers and facilitators to a successful transition across three systems; family, services and the wider social system.

Family system

Parents reported transition as a period of family adjustment and anxiety [23]. As a result, barriers in family systems were described as parents’ reluctance to allow their young adults opportunities for independence as a result of fear of their child’s vulnerability and their lack of assertive skills [22]. However, family members taking an active role in the young adult’s life was described as facilitating successful transition. Parents supported their child’s transition by advocating for services, teaching adaptive life skills and encouraging sibling support [22].

Service system

Barriers identified in the service system by parents included; a lack of information on available services and supports in developing transition plans, lack of communication and collaboration between families and services, poor person-centred planning and difficulty accessing services [5]. Parents felt that problems at the system level resulted in post-school leavers being less likely to participate in community activities, resulting in increased social isolation [16]. In addition, problems with current models of services delivery are evident in the finding that there are high levels of attrition from these services during the final year of school among young adults with intellectual disability [24].

Although limitations with the current models of service delivery were evident, a number of programs had been successful in supporting post-school transition among young adults with an intellectual disability [16]. Successful transition services were described as bridging the gap between schools and adult life in community participation and social inclusion [20]. This was achieved through these young adults attending transition programs located on university campuses during their last year of high school [21].

Wider social system

Employment is considered an important outcome in the transition process. Employment for all young adults creates a greater sense of autonomy and financial freedom from parents and young adults with intellectual disability often associate adult life with paid employment [24, 26]. Many of these young adults participated in job training programs, gaining community-based skills and work experience [21]. However, significant barriers to obtaining employment were competitive job markets and negative employer and community attitudes [22]. Parents described employers as more concerned about financial gain than providing opportunities for employment for young adults with intellectual disability [22]. Parents felt that a change in community attitudes would facilitate greater participation in the workforce for young adults and the development of social networks [22].

Quality of life

Community participation and social inclusion are crucial to all young adults’ quality of life [16]. Many young adults with intellectual disability with high support needs participated in weekly community activities [23]. However, a lack of programs which provided opportunities to engage in leisure activities in a supportive environment resulted in limited opportunities to socialise [22]. Ultimately, young adults with higher support needs are at risk of experiencing poorer quality of life as an outcome of the transition process [23].

Discussion

This systematic review found both qualitative and quantitative evidence to support the effectiveness of school to post-school transition programs in increasing community participation, friendships and the quality of life of young adults with intellectual disability. Current research demonstrates the need for improvement in existing models of service delivery, including the need for greater interagency collaboration, comprehensive information provision, early transition planning and a holistic approach. Such a holistic model approach is essential in encompassing the physical, emotional, social, and behavioural needs of young adults with intellectual disability for their successful transition to adulthood.

Limitations of this review include that only six databases were used to locate studies, however it could be contended that these databases were the most likely to identify research in this area. Further, the search was limited to published literature and did not include the grey literature, conference proceedings or manual searches of occupational therapy journals.

Overall the poor methodological quality of research in this field means that findings from this review must be interpreted with caution. In addition, current knowledge is limited in terms of its understanding of those factors which contribute to positive or negative outcomes for these young adults. In order to further understand the true effectiveness of transition programs for young adults with intellectual disability more rigorous research, larger population based samples and longitudinal follow-up is needed.

Transition programs must be viewed in light of both the strengths and limitations. The strengths of transition programs lie in the opportunities they provide for young adults with intellectual disability for social inclusion, community participation, access to work experience and the status of an adult [24]. However, current models of service delivery are dependent on parental advocacy for services and result in; prolonged family life adjustment and difficulties in sustaining open employment for the young adults [22, 23]. This review highlights the need for targeted interventions which meet the needs of young adults with intellectual disability and their families, in order to ensure that these young adults have equal opportunity to develop adult life roles [23].

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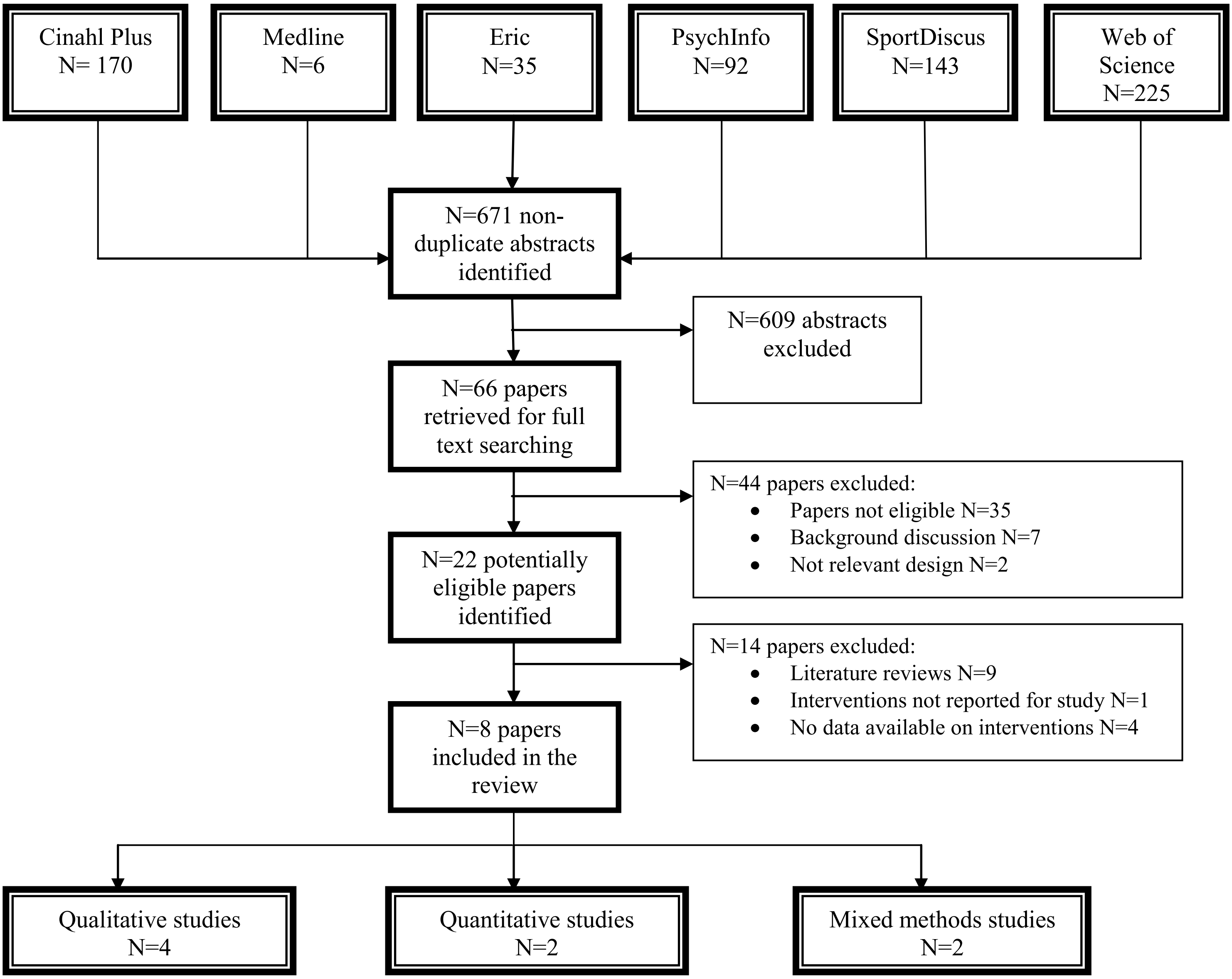

Figure 1. Flow chart of the study selection process

Table 1: Description of included studies: *Qualitative studies*

First author, year of Publication, country	Design, data collection and analysis techniques	Transition Program Criteria	Interventions (Focus of study)	Results	Summary of findings and themes	Methodological quality
Gillian [22] 2010 Ireland	Ground theory approach N= 12 Semi-structured interviews Three open-ended questions Axial coding analysis: process of relating categories to sub-categories	• Intellectual disability • Special education to post-school services • 19-24 years	N/A	• Meaning of transition • Psychological impact of transition • Barriers and facilitators to transition process: o Family system o Service system o Wider social system	Meaning of transition • Process of moving from school to employment • Ongoing Psychological impact • Parents stress and anxiety in relation to uncertainty of future • Frustration at lack of services Barriers and facilitators • Parental concern for child's vulnerability • Lack of information • Community attitudes and lack of friendships	Strong quality (score = 18/20)
Grigal [21] 2001 USA	Qualitative study 13 programs Questionnaires and semi-structured interviews CASAS measure basic adult skills and descriptive analysis	• Significant disabilities • Post-secondary public school programs • 18-21 years	Public school programs in post-secondary settings: • Age-appropriate peer interaction • University campus experience	Programs placed a strong emphasis on self determination and encouraged: • Functional skill activities • Job skills • Social skills training • Class and activity participation • Interagency, parental and student collaboration in transition planning	Transition planning and interagency collaboration resulted in: • Positive outcomes for the transition experience • Moving the young adults out of high school in their final year to university campuses • Postsecondary settings provided opportunities for the young adults to develop unique activities with community agencies to assist with post-school transition	Adequate quality (score=13/20)
Neubert [20] 2008 USA	Case study N = 16 Interviews and focus groups: open-ended questions Content analysis: verify coded themes	• Intellectual disability • Post secondary Transition services • 18-21 years	Public school program on a university campus incorporating transition practices: • Age-appropriate setting • Adult friendships	Service delivery models in transition lacked evaluation outcomes for students. Improvement in service delivery models required services to: • Conduct a needs assessment • Plan for implementation • Evaluate transition outcomes	Recommended transition practices included: • Independent life skills training • Work experience • Campus inclusion with same aged peers (friendships) • Social skills training • Self determination • Parental involvement • Program collaboration and evaluation	Strong quality (score = 18/20)

Note: CASAS, Comprehensive Adult Student Assessment System.

Table 1: Continued

Qualitative studies

First author, year of Publication, country	Design, data collection and analysis techniques	Transition Program Criteria	Interventions (Focus of study)	Results	Summary of findings and themes	Methodological quality
Caton [24] 2006 England	Qualitative study N=90 Semi-structured interviews and field diary note taking Documentary analysis Longitudinal study with 12-18 months follow up	• Mild intellectual disability • Transition experience • 15-18 years	N/A	High rate of participant attrition: • Original n=90, 12-18months post school n=23 • High rate of school attrition prevented young adults from accessing services	Aspirations of school-age participants included: • College • Work • Careership/ training	Good quality (score=16/20)

Quantitative studies

First author, year of Publication, country	Design, data collection and analysis techniques	Transition Program Criteria	Interventions (Focus of study)	Results	Summary of findings and themes	Methodological quality
Papay [12] 2011 Israel	Quantitative study 52 programs National survey Descriptive methods used for analysis of survey questions SPSS program	• Intellectual disability • Post-secondary education programs • 18-21 years	Post-secondary education (PSE) programs: • Characteristics of PSE programs serving young adults • Students in PSE programs and university class participation	• A high percentage of young adults with intellectual disability were enrolled in university classes, which were academically appropriate • However, only a quarter of those enrolled actively participated in classes	Purpose of PSE programs: • Employment/vocational training • Inclusion with same age peers • Gain independent living skills University class participation: • Varying types of classes provided according to rated academic ability • Varying levels of academic ability revealed a difference in class participation, higher academic ability meant greater class participation	Adequate quality (score=16/28)
Davies [23] 2009 Australia	Quantitative study N=218 Survey methodology SPSS program and descriptive statistics using frequency counts and percentages	• Intellectual disability • Post-school transition • 20-24 years	N/A	Transition has two key areas: Preparation for post-school life: • Employment, community activities and daily living Post-school outcomes for youth and families: • Paid work, leisure activities and young adult satisfaction	Parental perspectives: • Need for young adults to be incorporated in transition planning • Self determination is a critical component in goal-directed behaviour	Adequate quality (score= 17/28)

Note: SPSS, Statistical Package for the Social Sciences; PSE, Post-secondary Education.

Table 1: Continued

Mixed methods studies

First author, year of Publication, country	Design, data collection and analysis techniques	Transition Program Criteria	Interventions (Focus of study)	Results	Summary of findings and themes	Methodological quality
Eisenman [16] 2009 USA	Mixed methods study N =45 *Qualitative:* Semi-structured interviews via telephone Descriptive analytic techniques and case study research *Quantitative:* Adapted Supports Intensity Scale	• Significant intellectual disability • Transition-focused programs • 18-21 years	Transition-focused program: • Community activities • Social activities	Community activities • Parents reported concerns about supervision of young adults when engaging in community activities, particularly monetary or social interaction with strangers. • Parents felt that their children were vulnerable to being taken advantage of. Social activities • Families reported a desire for more peer activities that were age-appropriate and were not dependent on family participation	124 activities identified: • 42% youth participated without support • Support usually required in verbal prompts and gestures Unmet needs included: • Peer interaction • Public transport • Access to public places and services	*Qualitative:* Strong quality (score = 20/20) *Quantitative:* Adequate quality (score= 14/28)
Bhaumik [5] 2011 England	Mixed methods study N=140 *Qualitative:* Ground theory approach, using interviews Data appraisal for common themes and open coding *Quantitative:* SPSS version 12.0	• Intellectual disability • Transition process • 16-19 years	N/A	Key issues depicted by carers: • Difficulties in accessing services • Concerns about transition program, such as a lack of information and clarity • Areas of unmet needs, especially in day activities • Areas of improvement should include team co-ordination and involvement	Suggested improvements for transition planning included: • Defined eligibility criteria for service provision for the young adults • Provision of comprehensive information to parents • Effective practice principles underlying the transition process such as: ○ Communication ○ Co-ordination ○ Continuity of services ○ Choice for young adults and their families	*Qualitative:* Strong quality (score=17/20) *Quantitative:* Adequate quality (score=14/28)

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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.

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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.

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The meaning of well-being from the perspective of young adults with Down syndrome

Melissa Scott

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Previously research has examined the experience of living with intellectual disability and has focused on parents and carers’ perspectives and reflections regarding important issues for people with intellectual disability. Although parental and carer perspectives have been relevant and influential in research, the views of the people with intellectual disability themselves have been overlooked. The purposes of this study were to explore what makes for a ‘good life’ form the perspective of young adults with Down syndrome and to identify the barriers and facilitators to participation. Twelve young adults with Down syndrome participated in individual and group discussions. Analysis of the transcripts revealed four main themes: *‘Feeling loved’*, *‘Hanging out with friends’*, *‘Making my own decisions’* and *‘My Dreams'*. These findings highlighted the participants’ desire for autonomy, particularly in the domains of living independently and employment. Family relationships and community services were described as both facilitators and barriers to their participation. Overall, the findings from this study revealed that the participants’ life perspective was positive, with a general consensus of, ‘*I have a good life’*. This study yielded many recommendations that could be integrated into transition models of service delivery for young adults with Down syndrome as they transition from adolescence into adulthood.

Melissa Scott
Dr Sonya Girdler
October, 2011

The meaning of well-being from the perspective of young adults with Down syndrome

[1]MELISSA T. SCOTT, [1]SONYA J. GIRDLER, [2]KITTY R. FOLEY & [2]JENNY BOURKE

[1]Department of Occupational Therapy, School of Exercise, Biomedical and Health Science, Edith Cowan University, Perth, Australia and [2]Telethon Institute for Child Health Research, University of Western Australia, Perth, Australia

Abstract

Previously research has examined the experience of living with intellectual disability and has focused on parents and carers’ perspectives and reflections regarding important issues for people with intellectual disability. Although parental and carer perspectives have been relevant and influential in research, the views of the people with intellectual disability themselves have been lost. The purposes of this study were to explore what makes for a ‘good life’ form the perspective of young adults with Down syndrome and to identify the barriers and facilitators to participation. Twelve young adults with Down syndrome participated in individual and group discussions. Analysis of the transcripts revealed four main: *‘Feeling loved’*, *‘Hanging out with friends’*, *‘Making my own decisions’* and *‘My Dreams'*. These findings highlighted the participants’ desire for autonomy, particularly in the domains of living independently and employment. Family relationships and services were described as both facilitators and barriers to their participation. Overall, the findings from this study revealed that the participants’ life perspective was positive, with a general consensus of, ‘*I have a good life’*. This study yielded many recommendations that could be integrated into transition models of service delivery for young adults with Down syndrome as they transition from adolescence into adulthood.

Keywords: Down syndrome, intellectual disability, well-being, quality of life

Introduction

Down syndrome is the most common known genetic cause of intellectual disability and occurs in approximately 1 in 650-1000 live births [1, 2]An increase in life expectancy due medical advancements and changes in community attitudes has resulted in the need for research to consider issues relating to quality of life and well-being for people with Down syndrome [3, 4]There is a particular need to describe well-being from the perspective of young adults with Down syndrome as the transition from school to post-school [5]

In the literature the terms quality of life and well-being are used interchangeably, however well-being is not synonymous with quality of life [6]. Well-being is a subjective construct which encompasses the interaction of an individual’s mental, physical, emotional and environmental status, organising each status according to its degree of importance [7]. Although little is known regarding what young adults identify as well-being and the factors which affect it, well-being for young adults with Down syndrome can be conceptualised through the use of the *International Classification of Functioning, Disability and Health* (ICF) framework [8, 9]. The ICF recognises the interactions between the contextual factors and its impact on the young adult and highlights the importance of understanding the individual's own perspective of their well-being [8].

There are multiple contextual factors that may influence quality of life and well-being for young adults with Down syndrome. Environmental barriers such as negative community attitudes influence the acceptance and involvement of young adults with Down syndrome into the community [10].These attitudinal barriers impact on the young adults' opportunities for employment, community living and consequently social interaction [11].Young adults with Down syndrome are also often restricted in their community participation by parental attitudes, which limit their decision making and transition to independence [11].

Contextual factors including parents' availability of time to arrange social meetings, parental mental health state and access to community supports impact friendships for young adults with Down syndrome [12]. Friendships may make the difference between integration and isolation into the community for the young adults, both of which outcomes impact of their quality of life [13]. However, research suggests that opportunities for maintaining friendships and improving social interaction for young people with Down syndrome are often limited to less than once a week [12].The maintenance of friendships is particularly difficult once young adults with Down syndrome transition from school to post-school as the opportunities for daily social interaction are reduced [12]. The importance of effective school transition programs is being increasingly recognised in preparing and supporting the young adults with Down syndrome into adulthood [14].

The impact of contextual factors on quality of life and well-being for young adults with Down syndrome and the common practices of parents and carers serving as proxies in research have lead to the need for research to describe the young adults' view regarding their well-being. In addressing this need, the purpose of this study was to explore and define the meaning of well-being from the perspective of young adults with Down syndrome and to describe the facilitators and barriers to their participation.

Methods

In order to describe the meaning of well-being from the perspective of young adults with Down syndrome, a methodology which ‘gave voice’ to their views and perceptions was needed. As such, a qualitative methodology was chosen. Qualitative methods allow for the generation of rich data, where information is limited [15]. Qualitative interviews facilitate the exploration of the participants’ perspectives on their lives, experiences or beliefs regarding a specific phenomenon, as expressed in their own words [16]. This was of particular use when interviewing young adults with intellectual disability.

Sample

A purposive sample of twelve young adults with Down syndrome were recruited from participants in the Down syndrome *NOW* study [17], and from an existing group run by the Down Syndrome Association of Western Australia. Eligible participants met the following criteria: young adults with a clinical diagnosis of Down syndrome, between the ages of 18-30 years and living in the Metropolitan or regional areas of Western Australia. Participants had to be able to speak comprehensibly or with mild speaking difficulty.

An information letter briefly outlining the study and the time commitment involved was sent to parents of the participants. The purpose and procedures involved in the research was explained to the participants in plain language. Informed consent was obtained from the participants. The Edith Cowan Human Research Ethics Committee approved the research protocol.

Data Collection

Discussions were held with participants at both the individual and group level. Two sessions were conducted with an established social group for young adults with Down syndrome at a community centre and one group was held in a regional location. Discussions were facilitated by the primary researcher and three research assistants.

Individual discussions were face-to-face encounters between the researchers and the participants, which allowed each participant to express their perspectives in their own words [16]. The individual discussions explored personal and social matters. After approximately twenty minutes the participants formed a group discussion, which allowed for collective reflection and sharing of experiences [18].

Both individual and group discussions were directed by an interview guide (See Appendix A). The interview guide consisted of seven open-ended questions, which were loosely followed throughout each session. The interview guide explored the young adults’ ideas of what made them happy or sad, what helped or hindered their participation and, overall, what defined ‘a good life’ for a young adult with Down syndrome. This guide was applied in a flexible manner with questions according to the participants’ comprehension level, allowing for unexpected responses and issues to be raised by participants [19, 20]. .

Participants’ responses and ideas were recorded on butcher’s paper by the participants themselves or with assistance from researchers. Group discussions were audio recorded. Although additional participants may have assisted in reaching saturation, three groups produced sufficient data with emerging concepts, patterns and themes.

Date Analysis

All recorded discussions and butcher’s paper notes were transcribed verbatim and exported to Nvivo, [21] which assisted with data management. The open coding method as described by Strauss and Corbin (1990) was used to name, compare and categorise data. Significant statements were extracted from the raw data and were conceptualised and coded accordingly for further analysis [22]. Newly coded data was then grouped into broad categories and further analysed in relation to similarities and differences in the data sets [22]. These were then organised into the major themes [16].

Trustworthiness of the findings was achieved through multiple strategies. A review of the findings was undertaken by the executive of the Down Syndrome Association of Western Australia to consolidate the findings ensure credibility [23]. An expert in the field of qualitative research employed a further review of the coding to enhance the credibility of the findings. Purposive sampling was used to specifically select young adults with Down syndrome, who would be able to give expert comment regarding the purpose of the study [23]. An audit trail recorded coding decisions, date analysis and the critical thinking process [24]. Reflexive journals were also used to record ideas and assumptions in relation to the data, which were then checked by an expert colleague, to ensure it had not been influenced by personal biases [23].

Findings

Participant Characteristics

A total of twelve young adults with Down syndrome (six men and six women) participated in group discussions. Participants' ages ranged from 18 to 29 years (mean = 21 years). The majority of participants were living at home with their parents (*n*=10), one lived with a friend and one lived independently in close proximity to her parents' house. All but three participants experienced mild difficulty in speaking, with issues relating to their articulation. However, all participants' speech was appropriate and intelligible. All discussions lasted approximately 45 minutes. Data analysis revealed that for the participants in this study the meaning of well-being could be described according to four themes: *'feeling loved'*, *'hanging out with friends'*, *'making my own decisions'* and *'my dreams'*. As seen in figure 1.

Theme One: ***'Feeling loved'***

Participants' discussions were dominated by the importance of having meaningful relationships in their lives. Meaningful relationships were described as 'feeling loved', 'spending time together' and 'cuddles and kisses'. Participants described meaningful relationships in the context of relationships with family, friends, intimate partners and work colleagues:

> *It makes me happy being with friends and people at the community club (Andrew).*
>
> *Spending time with my family and my grandparents. I feel loved (John).*

According to Erikson, the transition from adolescence to young adulthood is a very influential period in the young adult's life [25]. This stage is described as the process of identity formation versus role confusion, whereby the young adults are attempting to establish their sense of self in relation to their parents, friends and intimate partners [25]. For young adults with Down syndrome it has been recognised that the reforming of these meaningful relationships during this stage is critical to their identity formation and well-being, and may often be seen as a period of confusion and stress [4].

Family Relationships

All participants relied on their parents to provide a secure environment where they felt loved, accepted and encouraged. Parents were also described as providing the young adults with opportunities to learn the skills needed to become independent. Overall participants described their relationships with their parents as positive and supportive. Jack, a 21 year-old young man described how his parents and carer helped him to negotiate the challenges of becoming an independent man:

> *My parents have helped me practice to live by myself. Things like cooking and shopping. My Dad and carer give advice about relationships, manners with girls, talking about women, what they want, learning to be a gentleman.*

Despite participants’ need for parental guidance, their desire for autonomy and recognition as a young adult often lead to conflict within the family. Participants felt that their parents, as well as their siblings were too *‘controlling’* and enforced *‘too many rules’* upon them. Many of the young adults expressed that they felt *‘smothered’* by their families:

> *It’s too hard for me to control my family. They boss me around like making me go to bed early, especially my sister. There are too many rules (John).*
>
> *I hate being told what to do (Jack).*

Research has highlighted that parents of young adults with Down syndrome play an essential role in creating and moulding the identity of their adult children [11]. For young adults with Down syndrome family relationships are central in shaping their attitudes and values, helping them to develop a clear idea of themselves as an adult [26]. Findings from the present study were similar to those of Docherty and Reid (2009), who described parental attitudes of young adults with Down syndrome as maintaining values and expectations, which reinforced the ‘parent-child’ relationship, which inhibited the young adults’ independence into adulthood. Consistent with findings from this study, many parents continued to take an authoritative approach to parenting their young adults with Down syndrome, continuing to make decisions for them without discussion or consultation [11]. Craig (1996) proposed that this authoritative approach to parenting may re-enforce child-like behaviours in young adults with intellectual disability.

Friendships

Participants in this present study described friendship as highly valued and as making important contributions to their feelings of inclusion, acceptance and self-esteem. Friendships provided opportunities to participate in activities together, to *'tell jokes'*, socialise and encouraged friendly rivalry between football teams. Participants were enthusiastic regarding their friendships:

> *I like going out with friends to the pub and movies (Jack).*
>
> *On Friday evenings I go to the café club. I do some activities and games. Lauren and me we do dancing on Friday evenings (Andrew).*
>
> *I do weights with my best friend. He is a really good friend (Andrew).*

Friendships and social contacts are recognised as being particularly important for people with intellectual disability [27]. Friendships have been described as significant in establishing and developing self-identity through engaging and reminding each other of their 'life stories' [28]. Such friendships are reinforced through meeting regularly, encouraging each other and participating in activities together [28].

Peer relationships are powerful especially during young adulthood and have the ability to foster both positive and negative social experiences [29]. Participants in this study described occasions when they had been *'bullied'*, *'left out'* or *'teased'*. Participants described these experiences as *'bad memories'*:

> *At school there were bullies, they teased me. I got bullied at high school, I was embarrassed (Jane).*
>
> *I don't like it when friends leave me out, or other people out (Jack).*
>
> *I like nice people, but some people are nasty and tease me. I get sad when people at work tease me (Jane).*

Many young adults with intellectual disability are bullied physically, verbally or emotionally, which often results in social withdrawal, loneliness and school drop-out [30]. Many young adults with intellectual disability who are bullied, lack the problem-solving skills necessary to take control over their situations and need to be taught how to problem solve, manage the stress of being bullied and develop coping strategies [31]. In this study, Simon, aged 18 years, described his strategy for dealing with bullying at his workplace:

> *I wear earplugs at work when people are bullying me so I can’t hear what’s going on (Simon).*

Coping strategies have been found to help mediate the negative effects and stress of being bullied [31]. In this study, Simon described an innovative coping strategy to overcome his workplace bullying. Such a strategy is referred to as an avoidance approach, which involves ‘escaping’ the threatening stimuli and it reduces associated stress from the bullying [31]. However, it does not resolve the problem. Given these findings, it may be beneficial to encourage parents and teachers of young adults with intellectual disability to implement problem-focused coping strategies in the lives of the young adults [31].

Intimate Relationships

Participants described intimate relationships as having a *‘boyfriend’* or a *‘girlfriend’*. Intimate relationships for participants were not typically characterised as physical and romantic, but were rather considered in part a status symbol of really being an adult. Intimate relationships were expressed as an opportunity to have fun with a member of the opposite sex by *‘just hanging out together’*. Participants seemed to be more concerned with the desirable status of having a partner than companionship:

> *I like spending time with my boyfriend. We have been together for one year. We met at the theatre. But I might find someone who is more handsome than my boyfriend and has better behaviour (Kate).*
>
> *I’m happy spending time with my boyfriend, just hanging out (Jane).*

The attitudes of young adults with intellectual disability toward intimate relationships vary according to their level of disability [32]. Young adults with mild intellectual disability consider ‘dating’ as an opportunity to have fun with a partner, whereby most interactions occur within a group setting [26]. The focus of an intimate relationship for these young adults has been described as physical attraction and the desire to raise awareness within the friendship group that they have a relationship status. Despite simple attitudes toward intimate relationships, many young adults with intellectual disability express the hope for marriage and a family, much like the general population [10]:

> *I dream of getting married (Kate).*
> *I would like to be a mum and have children of my own (Julia).*

Theme Two: ***‘Hanging out with friends’***

Participants enthusiastically described their active participation in the community, with the majority able to independently undertake community activities including, catching public transport and cycling in and around their neighbourhood. However, in activities where supervision or assistance was needed, participants relied on parents, siblings and carers for support and guidance. Participants engaged in a variety of community activities including; education, employment, social activities and leisure pursuits.

Education

Continuing their education post high school was only considered important and practical for a few participants. These participants attended weekly classes at technical colleges to further their learning in practical skills such as, cooking, typing and life skills:

> *On Wednesdays I go to TAFE. I do maths and life skills. On Thursdays I do cooking (Andrew).*
> *At TAFE I do computer, typing skills and business. I like going to TAFE. My girlfriend goes to TAFE we do maths together (Jack).*

Higher educational attainment has been associated with better employment outcomes for young adults with intellectual disability. Parents of young adults with intellectual disability who have higher education are also more able to influence employment outcomes [33, 34]. Educational attainment may also be seen as a barrier to employment, as young adults with intellectual disability with a lower education such as primary school or early secondary school only have limited work opportunities [33]. Given these findings, it may be beneficial to encourage young adults with intellectual disability to pursue further education post-school to facilitate their acquisition of life skills and enhance their employment outcomes [34].

Employment

Having a job was held in high regard by participants. Participants in this study engaged in open and sheltered employment. Open employment included working in hospitality, fast food stores, department stores and waitressing.

> *I work at KFC. I look after the paper stock and boxes. I like it (Julia).*
>
> *I work waitressing, it's not too bad (Kate).*
>
> *I work at Kmart on Wednesdays, Thursdays and Fridays (John)*

All participants who worked in sheltered workshops worked at Activ, an organisation that provides community support for people with intellectual disability across Western Australia. Participants working at Activ worked in the areas of woodwork manufacturing, gardening and cleaning services:

> *I left school in year 11 and started working at Activ. I learnt woodwork and can make pallets and chairs. I like going to work and looking after the machines (Kyle).*
>
> *I work doing gardening, cutting bushes and mowing lawn. I enjoy it (Simon).*

Employment offers many benefits to all individuals including, a sense of purpose in life, income, social relationships and a structured daily routine [35]. Participation in employment can help young adults with intellectual disability to feel appreciated, important and included, employment can further contribute to an individual's identity [35, 36]. Employment for young adults with intellectual disability positively influences mental well-being with those who are employed reporting higher levels of self-esteem, psychological well-being and lower levels of depression [37]. Clearly, employment is highly valued by young adults with intellectual disability and has a positive impact on quality of life and well-being [37].

Social and Leisure Activities

Similar to most young adults, participants in this study described their social activities as including, '*hanging out with friends*', attending social events such as football games and concerts, and participating in community groups. Many of the participants' friendships and socialising occurred with other young adults with Down syndrome within their community social group:

> *Going to the Miley Cyrus concert makes me happy (Julia).*
>
> *I like going out with friends, meeting them at the pub for beers. I like drinking heavy beers (John).*
>
> *On Mondays I go to the community centre for drama classes with some of my friends from one of my community clubs (Andrew).*

Leisure is considered a voluntary activity, which people engage in through personal choice and preference with the main goal being to ‘have fun’ [38]. Participants in this study engaged in leisure activities both individually and in groups. Leisure activities described included; sporting activities, listening to music and playing with pets:

> *On Tuesdays I start my day by playing golf with my best friend. We hit a lot of balls, I’m good at golf, and I like it. Then we go to the gym (Andrew).*
>
> *I enjoy music, acting and dancing. Ballroom dancing is my favourite and I really want to perform on stage one day (Kate).*
>
> *I like listening to music by Jessica Mauboy, Cassie Donovan and the Bee Gees and Jazz music. My favourite band is the Bee Gees (Julia).*

However, despite participants engaging in active leisure pursuits, many expressed their preference for more sedentary and solitary activities. Participants described these activities as including, watching T.V., reading and playing virtual games.

> *I like playing Nintendo games and using the Wii wheel for active sport games (Justin).*
>
> *I like playing Wii games. I also enjoy watching T.V. My favourite T.V. shows are, Masterchef, Dancing with the Stars and Downton Abbey (Jane).*
>
> *I like cards, watching movies and playing games on my Playstation 2 (Kyle).*

Young adults with intellectual disability do not necessarily achieve leisure participation despite living within the community [38]. The amount of time spent in solitary and sedentary activities is not controlled and can lead to a loss of social skills and social isolation for young adults with intellectual disability [10]. This is a major concern of parents, as many young adults with intellectual disability lack the knowledge and skills needed to take control over their own leisure participation and friendships [38, 39]. However, research has also highlighted the importance of contextual factors including parents' availability of time to arrange social meetings, parental mental health, income status and access to community supports in influencing the leisure participation of young adults with Down syndrome [12].

Our findings described that participants in this study were actively involved in their community, participating in a variety of different activities with opportunities to engage and build relationships. Overall participants' experiences with activities were described as positive. Despite participants often engaging in sedentary activities, many of them viewed this a time to *'relax'* from their other daily obligations. However, as participants in this present study being recruited from existing social groups it is likely that they represented a group, which had high levels of parental support and involvement. Our findings support those of Duvdevany and Arar (2004), who reported that young adults with intellectual disability lack the skills required to take control over their own leisure participation. However, Duvdevany and Arar (20024) continued to describe that the impact of family support systems and an environment which encourages freedom in leisure choices and social activities was also responsible for participation in the community for young adults with intellectual disability.

Theme Three: ***'Making my own decisions'***

'Making my own decisions' was described by the participants as having the opportunity to choose activities, clothing or food that they enjoyed without their parents influence. Participants described their desire for freedom in their lives as wanting to live by their *'own rules'* without *'nagging'* parents.

Autonomy

Participants were collectively striving for autonomy in their lives. Participants described their desire to have control over their own lives, decrease their dependence on their family members and make their own decisions. Much like their non-disabled peers, participants wanted to achieve autonomy in their decision making:

> *A good life is being my own boss and living by my own rules (John).*
>
> *I want to be an adult, it makes me happy because that's how you grow up and learn to do your own chores (Lauren).*

> *I make my own decisions what I do. I'm wearing proper clothes and that's the best part. Looking nice is important (Kate).*

The process of establishing a sense of self separate from parents is a major task in young adulthood [29]. Achieving autonomy is an important factor in achieving this sense of self [29]. However, despite parents of young adults with intellectual disability recognising the need for autonomy in their child's life, many are aware that their young adults will always require ongoing assistance and support in their lives [11]. This often results in conflict and a restrictive parent-child relationship [11].

However, our findings support those of Shogren and Broussard (2011), which discuss the importance of encouraging young adults with intellectual disability to be involved in making their own decisions and determining their own futures. This may be achieved through parents and carers mentoring and encouraging the young adults with intellectual disability to be self-determined in their behaviour [40]. Self-determined behaviour for young adults with intellectual disability will promote choice, control and self advocacy in their daily lives [40].

Living Independently

For all participants the desire to leave home and live independently was of great importance. Participants viewed living independently as a chance to live without rules and parental control. Many participants wanted the same privilege as their siblings who had left home.

> *I live at home and I don't like. I would like my own place (Andrew).*
>
> *I dream of moving out of home it would be good. I'm an adult; it's a head start. I have three older sisters and they have all moved out (Kate).*

Even though participants considered a *'good life'* to include living independently, only two participants had achieved this status and continued to rely on their parents and carers for support:

> *I like living with my house mate (Kyle).*
>
> *I really like having my own place. I keep myself busy. But on Mondays I've got a carer who takes me shopping (Jane).*

Research has highlighted that parents of young adults with intellectual disability consider encouraging independence as an important life factor [41]. However, many parents feel that due to a lack of support and services they have little choice but to take control over the direction of their young adult's life [41]. As a result parents tend to limit their young adults' independence, becoming overprotective and often finding it difficult to gauge the level of independence achievable by their child [41].

A suitable compromise for parents and young adults with intellectual disability may be 'supported' or semi-independent living accommodation [42]. Semi-independent living involves one to four young adults with mild intellectual disability living together with regular part-time support from an accommodation support agency [42]. Positive outcomes of semi-independent living have been reported to be improved quality of life, autonomy, social integration and personal choice [42]. Given these findings parents of young adults with intellectual disability may need to be made aware of alternative options for community-based living.

Work opportunities

Participants described that having the opportunity to work and to earn money was an important factor contributing to a *'good life'*. Participants had mixed attitudes towards money. A few participants felt that saving their money for something more expensive, such as a holiday was more important than spending it on accessories, alcohol or sports betting:

> *I like work and getting paid then I can save my money (Jack).*
> *I am saving my money for my holiday to Sydney (Kate).*
> *I like work. I like having money so that I can buy jewellery (Julia).*

Although the majority of participants worked at least twice weekly, many expressed the desired to work more hours or work in a variety of environments. Due to their limited income participants felt that they were restricted in their community involvement, with insufficient funds to support their social participation:

> *Not having enough money stops me from doing the things that I want to do (Kyle).*
>
> *Not having enough money stops me from doing what I want to do like buying a house. I want to live independently like Jane (Kate).*

Participants described applying for new jobs, however, they felt that their choice of work was dependent on the opportunities that employers were willing to provide. Several participants described how at times their current jobs were preventing them from pursuing and achieving their life goals.

> *I hope to get another job at a café serving customers but I'm waiting to hear back from the manager to see if he has hours for me (Jane).*

> *I'd like to be famous with cameras and make more money, but I'm stuck in a café (Kate).*

Despite the benefits gained from employment for young adults with intellectual disability, equal employment opportunities are limited [43]. Even when employed young adults with intellectual disability are often hired for low-skilled, low-paid and casual positions [43]. Research has also highlighted that employer perceptions and attitudes play an important role in the success of employment for young adults with intellectual disability [43]. In order to overcome possible employer misconceptions, the role of supported employment agencies is to 'market' the young adults with intellectual disability to the employer [44]. These employment agencies profile the young adults according to their work goals, aspirations, strengths and weaknesses. Furthermore they discuss and explain their needs and benefits of employing a young adult with intellectual disability to the employer, with the desired outcome of achieving employment for the young adult [44]. Supported employment is important and necessary for creating equal work opportunities for young adults with intellectual disability.

Theme Four: ***'My Dreams'***

According to Erikson (1982) as adolescents move into young adulthood their search for their sense of self will begin to fuse with their identity of whom they are and of whom they hope to become. Overall participants' discussions were dominated by their future dreams, their hopes for a marriage, a family of their own, to live independently and most importantly to have the opportunity to drive.

Opportunity to drive

Many of the participants described their desire to learn how to drive and own a car. Participants discussed their frustrations in having to depend on their parents and siblings to drive them. Many of the young adults felt that having their license would give them the freedom to drive to the destinations of their choice and it would, *'just make things easier'*:

> *If I got my licence if Mum was busy I could go out (Jane).*
>
> *I don't have a driver's license and that stops me from going to the places I want to go to. I want to get my license at some stage (Kate).*
>
> *If I could drive a car it would be easier. My sister can drive and she drives me. She is over 17 and she has just got her licence (Andrew).*

Community mobility is essential for all people to engage in their valued occupations and positively impacts on employment, self-esteem, independence and quality of life [36, 45, 46]. Young adults with disabilities are faced with barriers which limit their mobility opportunities and result in dependence on family members for transportation [45]. The effect of not having a driver's license for young adults with Down syndrome results in them having to depend on family members, often hindering their leisure and social activities and their attempts to become independent [45].

In this present study it appeared that many of the parents of the young adults with Down syndrome had not yet addressed the difficult topic of their young adults possibly never being able to drive. Given these findings it may be beneficial for parents and community services to address this issue through encouraging the independent use of public transport.

Marriage and a family

Participants frequently expressed their desire for marriage and starting a family. In particular a few of the young women in this study discussed the prospect of becoming a mother and raising children. In this study many of the participants were already couples and openly discussed that at some point in the future, marriage, children and a life together was the next inevitable step in their relationship. Lauren, a 23 year-old woman described her plans to become a mother:

> *I want to become a mother some day and have children two boys and two girls.*

Kate's partner in the group commented:

> *Hey I can be the Daddy; I want to keep you happy (John).*

Many of the participants described similar plans for their future with their partners:

> *I dream of moving out and getting married. I'd like to be a married woman; I've got a boyfriend. My sisters have children. I wish I could have children (Kate).*

> *I like spending time with women. I would like to get married some day (Jack).*

Despite changing community attitudes towards intimate relationships of people with intellectual disability, the attitudes of parents of these young adults remain sensitive [47]. Parents of young adults with intellectual disability tend to have a conservative view of marriage and the sexuality of their young adults [47]. Parents are often reluctant to address these difficult issues, despite increasing positive community attitudes towards sexual expression and marriage for people with intellectual disability [32].

Due to conservative parental attitudes many young adults with intellectual disability have a low level of knowledge regarding safe sex practices, contraception, sexually transmitted diseases and the difference between sexual consent and abuse [32]. There is a need for young adults with intellectual disability to receive sex education both for their protection and knowledge [32]. In this study the young adults expressed their desire for intimate relationships, marriage and parenthood.

Moving out of home

As previously discussed in this study, participants' discussions were dominated by the desire to live independently. However, despite most participants not yet having achieved independent living, the aspiration to *'move out of home'* and own a house was consistently described as symbol of becoming an adult:

> *I want to live all by myself in the future (John).*

Many of the participants described detailed plans in relation to what they wanted for their future. Andrew, a 21 year-old young man described that when he moved out of home he would live nearby to his relatives:

> *I would like my own place. I want to move down south to Dunsborough. I want my own place in Dunsborough. My grandparents are in Busselton and my aunty is in Margaret River. I want to live down there (Andrew).*

Another young man, Jack described his future plans:

> *I want a house near the beach with a movie theatre in the house (Jack).*

The process of leaving home is an important factor in transitioning into adult life and is most frequently associated with achieving independence [48]. Leaving home is considered a period, when young adults begin to establish an identity separate from their parents [29]. When confronted with the task of leaving home, normal developing young adults experience conflicting feelings between excitement and fear of not being able to cope with everyday tasks and maintain meaningful relationships [49]. However, as for participants in this study their focus is on leaving home only, often without concern for household management and responsibility [11].

Consequently, if young adults with intellectual disability are not appropriately supported in their independent living they may experience difficulties in their daily activities of self-care, personal safety and money management [42]. Although they strive for an independent identity, it is highly likely that many of these young adults will continue to rely on their parents for support, and never truly separate their identity from that associated with their parents [11].

Discussion

Overall, the findings from this study revealed that the participants’ life perspective was positive, with a general consensus of, *‘I have a good life’*. Throughout this study participants described their desires for autonomous behaviour, independent living and the recognition as a young adult. These desires for achieving such milestones are similar to those of their normal developing peers, including the rights to the same life opportunities. Participants’ desires can be explained according to Erikson’s developmental stages, whereby the participants were experiencing conflict between developing their adult identities, whist also trying to re-establish their roles and relationships in the context of family, friends and society [25]. Our findings reflected their conflicts in identity formation, as participants considered themselves to be young adults, but felt their parents inhibited their independence. Previous research has described the transition into adulthood for young adults with Down syndrome as a period of confusion and stress for families [5].

The findings of this study differed from those of previous qualitative work. Many previous studies have examined the perspectives and reflections of quality of life for people with Down syndrome, however these studies have been described from either the parental or carer perspectives [4, 10, 11]. In contrast, the present study has examined well-being from the perspective of young adults themselves, including their views and perceptions on the barriers and facilitators to their participation. Findings across studies, including this study have described a ‘good life’ to include supportive social networks accommodation/independent living options, employment opportunities and participation in recreation and leisure activities. Parents were described as both assisting and hindering their participation and further support was needed in relation to discussing sexuality, relationships and the prospect of the participants not attaining their driver’s license, which were not adequately addressed.

Throughout the discussion, findings from the current study have indicated many recommendations that could be integrated in models of service delivery, particularly as the young adults with Down syndrome transition from school to post-school. Areas for future intervention include services aimed at training and attaining employment, community workshops directed at teaching life skills and encouraging self-determination and lastly, educational workshops regarding managing relationships with parents, friends and intimate partners for the young adults with Down syndrome. In these workshops issues such as sex education, managing conflict with parents and problem-solving skills in relation to bullying will need to be addressed. This study highlights that although the challenges for increasing life expectancy have been achieved for people with intellectual disability, the task now for health professional is to equally match life expectancy with purpose and quality for these individuals.

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INTERVIEW GUIDE

'What makes a "good life" from the perspective of young adults with Down syndrome'

1. How do you start your day?

2. What happens after that? What do you do for the rest of the day?

3. What makes you feel happy? We want you draw a picture of all the things that make you feel happy. Tell us what each of these pictures mean to you?

    a. What are your favourite things to do?

4. What helps you do the things you want to do?

    a. Do your parents and brothers or sisters help you to do things?
    b. What things do you on your own?

5. What makes you feel sad? We want you to a draw a picture of all the things that make you feel sad.

    a. What things don't you enjoy doing?

6. What stops you from doing the things you want to do?

7. What do you enjoy most about being a young adult? What makes a good life?

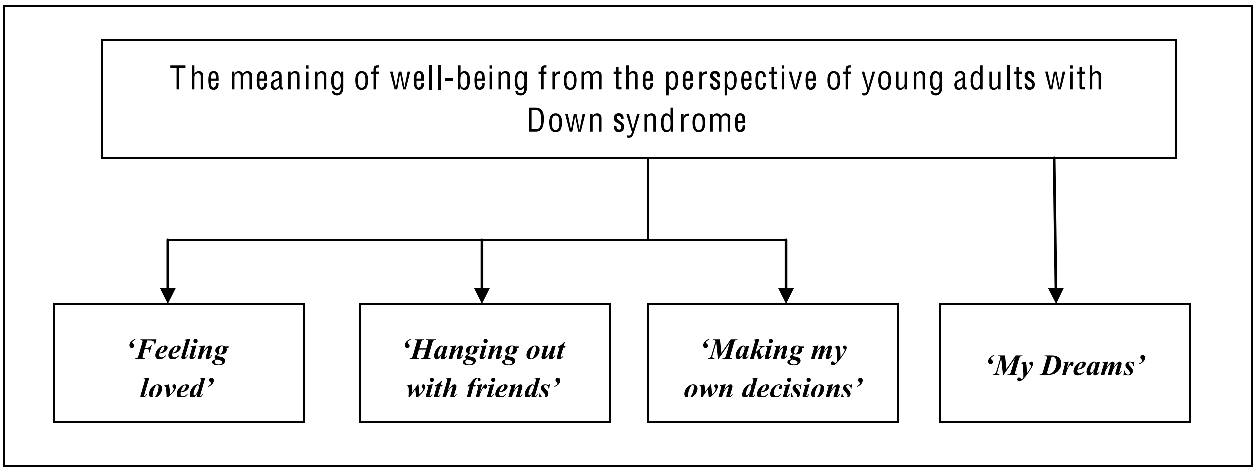

Figure 1. Flow chart of the major themes

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Structure of Paper

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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.

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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.

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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.

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