

A Somewhat Different Journey

Transition to adult living for persons living with Down syndrome

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Abstract

The family is the most important institution in providing care and support for a child. However, when a child is disabled, our general understanding of appropriate support might face new challenges. The experiences of families are closely linked to the outcome of the children in the family. Thus, the key role of the family is to provide a positive resourceful environment throughout the various stages of development in order to ensure successful transitions of its children. So far there has been little research aiming to understand the period of transition to adulthood exclusively for people with Down syndrome, and what facilitates a successful transition to taking on adult roles. This paper aims to identify social and demographic factors, individual intellectual and personality characteristics of the adolescents, types of family functioning, and public policy interventions that can act as facilitators for young people with Down syndrome as they age from adolescence to adult life. A successful transition to adulthood in this context is understood as taking on adult roles. In this study being in paid employment will serve as the best example of a highly independent adult role. It should be noted that people with Down syndrome often differ significantly in their available resources and individual abilities. This study focuses on these differences within the group of Down syndrome young adults living in Western Australia.

1. Introduction

Since the early 1980s the life expectancy for people born with Down syndrome has increased remarkably (see e.g. Bittles et al. 2006, Roizen 2001, Bittles 2004, Leonard et al. 2002, Carothers et al 1999, Glasson et al. 2002, and Yang et al 2002). The two main reasons for this are: a) changes in access to primary healthcare, and b) advances in health technologies (Glasson et al 2002:390). Today, a person with Down syndrome is expected to live into his or her fifties and sixties. In addition, it has been identified in the literature that the implementation of a large range of policies, together with a transformation of societal attitudes, has led to that today a great majority of persons with Down syndrome growing up at home, whereas until a few decades ago these people would predominately have been placed in institutions. It is exactly these changes in age composition and inclusion in the family for persons with Down syndrome, which provide the basis for this paper.

At present, many children with Down syndrome grow up going to school and enjoying many of the same activities as other kids. Some transition to semi-independent living, but still the majority continue to live at home as long as possible, and are able to participate in continued learning or to hold paid jobs. Yet, only limited research has been done in documenting the transition into adulthood for young adults with Down syndrome, and what facilitates Down syndrome young adults in taking on adult roles where a relatively high level of independence is required.

Regardless of whether young adults are living at home or semi-independently, employment is a key aspect of participation in the society. A regular workplace is the principal context for interactions, social standing, and earnings for all persons as they finish school, - and especially for Down syndrome persons, many of whom will never live independently, become a romantic partner, or become a parent. This paper investigates what facilitates Down syndrome young adults to transition to paid employment, and presents some of the most recent and unique data on the functioning of young adults with Down syndrome and their families collected in Western Australia by the Telethon Institute. The aim is to provide new insights of the context of this particular to the transitional stage for young adults living with Down syndrome, and to answer why some young adults with Down syndrome are more successful in taking on the adult role of paid employment than are others.

2. Down syndrome

Down syndrome is a genetic disorder associated with limits on intellectual abilities and adaptive behaviors (conceptual, social, and practical skills people use to navigate their everyday lives). Most people with Down syndrome have IQs that fall in the mild to moderate range of mental retardation, and the majority may have delayed language development and slow motor development (Roizen 2001:38). However, it is important to highlight that the physical and mental limitations that people with Down syndrome experience can differ greatly from person to person.

Down syndrome affects 1 per 650-1000 live birth and is the most common diagnosed genetic cause of intellectual disability (Bittles et al 2006). In Western Australia, as well as throughout most of the western world, the changes in maternal age distribution (increase in women's age when giving birth)¹ are believed to have increased the number of children with Down syndrome. Bittles et al (2006) shows that in Western Australia the overall prevalence of Down syndrome - counting live births, stillbirths and terminations of pregnancy – increased from 1.1 per thousand in 1980 to 2.9 per thousand in 2004. In this same period changes occurred in maternal age. In 1980, 4.8% of women giving birth in Western Australia were age 35 or older, and in 2004 this proportion increased to 18.6%. Of these 18.6%, 11.7% were first-time mothers (Ibid). The issue of prenatal screening and selective abortion is also believed to have affected the overall prevalence of Down Syndrome. Until 1991 of Down syndrome fetuses, but in 1991 second trimester maternal serum screening was introduced (Ibid). From 1980 to 1991 the total prevalence increased from 1.1 to 1.6 per thousand births (Birth Defect Registry 2006:18). In 1999, new methods for screening were introduced and first trimester screening became possible. From 1999 until 2004, the total prevalence of Down syndrome increased from 1.9 to 2.9 per thousand (Bittles 2006:2). However, it should be kept in mind that the introduction of first trimester screenings probably contributes to this increase in total prevalence since 1999, due to the fact that fetuses that may previously have been lost spontaneously before 20 weeks of gestation are now being recorded (Ibid). In 2006, about two thirds of Western Australian women have first trimester screening for Down syndrome (Ibid).

¹ Women age 25 and above are at increased risk of having a baby with DS. (Bower et al 2000:213) One example is that at age 20 the risk is 1 out of 1500 and at age 45 it is 1 out of 25.

In the context of Western Australia prenatal screening is available as a part of universal healthcare (AIHW:2006). Nonetheless, it has been identified in prior studies on access to healthcare in Australia that for example Indigenous Australians' access and health practices in some instances diverge from the practices of the white population. This difference in health practices is mainly due to the fact that Indigenous Australians are more likely to live in very remote areas of Australia compared to non-Indigenous Australians. Approximately 26% of Indigenous Australians live in remote or very remote areas of Australia compared to only 2% of non-Indigenous Australians (Ibid). Besides physical access, factors such as affordability of additional private health insurance, proficiency in English together with cultural barriers are also issues that prevent Indigenous Australians from taking advantage of the available healthcare (Ibid).

Unfortunately, there were no questions regarding race included in the survey instrument used to collect the data available for this study. The Birth Defect Registry notes that in general birth defects are more common in multiple births and male infants, and that even though that there is a lower prevalence of birth defects reported in Indigenous Australians' children, this is thought to be due in part to under-ascertainment of cases of birth defects in Aboriginal children (Birth Defect Registry 2006:7). In the data available for this study only 1 case is classified as living 'remote' using The Accessibility/Remoteness Index of Australia (ARIA).

Moving from the nature and prevalence of the genetic disorder of Down syndrome, to the physical health status of people living with Down syndrome, it is important to stress that a variety of health conditions are often seen in people who have Down syndrome. In this

study such health conditions can impact the young adults' level of everyday functioning, and thereby their ability to participate in paid employment. The parents/primary caregivers in this study were asked whether their children had any current problems or received continued treatment (including medication) for this condition, and whether their child had ever been diagnosed with one of the following conditions: heart, bowel or gastrointestinal, hearing or ear, eye, thyroid, muscle and/or bone, respiratory, and other significant health conditions. In Table 1 the proportion of the final study population experiencing such current problems or continued treatment (including medication) is summarized.

Table 1: Current Problems or Received Continued Treatment (including medication) Among Down syndrome youth Age 16 to 25 in Western Australia, 2004-2005 (N = 109)

	Number of cases	Percentage of final study population
Current problems/treatment	83	76.2
Heart	5	4.6
Bowel or gastrointestinal	11	10.1
Hearing or ear	24	22.0
Eye	55	50.5
Thyroid	25	22.9
Muscle and/or bone	26	23.9
Respiratory	13	11.9
Other	24	22.0
Ever diagnosed with any of the above problems	103	94.5

3. Adult Roles

Each individual experiences a life with Down syndrome very differently, which to some extent yields different levels of expectations about the future. The transition to adulthood Down syndrome young adults will experience might differ with regard to the range of available opportunities compared to those of the majority population. Yet, sociologists have not carefully investigated how young adults with Down syndrome and their families experience the transition to adulthood. In the case of Down syndrome young adults the institutional arrangements and the family resources needed will most likely differ from those of the majority population. Also, the developmental stages required in order to complete the transition to adulthood, might occur at a different pace and have different implications from those experienced by the majority population, meaning that the duration of each developmental stage often is longer and the transition might happen compared to young adults without Down syndrome.

In this study it is recognized that the transition to adulthood is a complex matter, and most often the process of taking on adult roles is interplay between agency and structure. This paper focuses on the resources available to the Down syndrome young adults and thereby the part of transition into adult roles related to structure. Yet, it is still acknowledged that agency holds crucial importance. Mechanisms frequently ascribed to the notion of agency in a life course perspective would be the process of individuals choosing appropriate institutional involvements, organizational memberships and interpersonal relations (Shanahan 2000:667). In other words, how mechanisms which capture young adults' plans and goals during the transition to adulthood, translate into actual outcomes. However, for Down syndrome young adults this type of agency is often

mediated through how their parents think about plans and goals for their child. Even though parents of Down syndrome children are as likely as any set of parents to wish for the best possible outcome for their child, the availability of appropriate opportunities that match the strengths of the Down syndrome child sometimes yields a navigation of structural resources different from the majority population. It is the point of departure in this paper that some resources may prove more salient than others in the transition into taking on an independent adult role. Taking on adult roles is here understood as an essential component in the transition to adulthood, and as occurring in a dynamic interplay between the Down syndrome young adults (and their families) and their social context.

Adult roles are most often defined as living independent from one's family, working in (full-time) paid employment, pursuing further education, entering a marital union (or cohabitation) and becoming a parent. A person is most likely to be involved in taking on multiple roles simultaneously, as for example becoming employed and living independently away from the parental family home. In this study the focus is on employment. One could argue that for Down syndrome young adults, living away from home or being in continued learning are also important indicators of self-sufficiency (see e.g. Thompson 1995, Marshek et al. 1999, Irwin 2001, and Hudson 2003). However, the primary concern in this study is what facilitates a successful transition to adulthood, understood as obtaining adequate degrees of self-sufficiency to live a relatively independent life. It is the assumption in this study that to be in paid employment reflects the type of societal participation that necessitates coping with situations requiring

adequate self-sufficiency to face the regularities as well as irregularities of an independent adult everyday life, without the supervision or help from specially trained staff and/or immediate family.

The final study population yields 109 Down syndrome young adults age 16 to 25. Less than 4 (3.6%) Down syndrome young adults are reported living away from the family home², only 2 (1.8%) Down syndrome young adults are reported to be in high school, and 1 (0.9%) is reported attending an adult education center. Information on romantic relationships or sexual behavior is not available. This type of information could provide insights into the prospects of marital (or cohabiting) unions that might strengthen aspirations to take on certain adult roles. Still, such relationships and aspirations are not necessarily capturing the type of self-sufficiency leading to navigate an adult everyday life independently, but rather provide emotional support in doing so. Also, due to the nature of the disorder, involvement in romantic relationships as well as independent living are more likely to happen after age 25 for this group of people. Finally, participation in paid employment is something that can and does happen for these Down syndrome young adults, which makes it an unique adult role to observe. In the final study population 56 (51.4%) Down syndrome young adults are engaged in paid employment. Employment is the major dimension of participation in which Down syndrome young adults vary, and is therefore the major focus of this study.

² Which matches what the literature has established in relation to the implementation of policies and transformations of societal attitudes?

4. Western Australia

When using data from Western Australia, some contextual conditions must be stressed. Overall Australia has had one of the strongest and most open economies in the world over the past decade. Australia's high economic performance – resting on strong growth, low inflation and low interest rates – has been the result of effective economic management and ongoing structural reform, along with a competitive and dynamic private sector and a skilled, flexible workforce (WHO/WPRO 2008). In addition, Australia has enjoyed a high standard of living since the nineteenth century, and has made a comparatively large investment in social infrastructure, including education, training, health and transport (Ibid). In Table 2 a comparison with the United States on the probability at birth not to survive to age 60, together with the percentage of the population living below 50% of the median income is provided. These two measures captures two basic dimensions of life quality within a population, namely to live a long and healthy life, and to have a decent standard of living (HDR 2007-2008).

Table 2: Comparison of Australia and USA on Two Basic Population Life Quality Measures

	Probability at birth of <i>not</i> surviving to age 60	Percentage of the population living below 50% of the median income
Australia	7.3	12.2
USA	11.6	17.0

In Australia, Social security and welfare benefits are available as well as specific support and services designed for people disability. In Appendix 1 an overview of the main forms of economic governmental support for people with disabilities in Australia are listed.

Note that some forms of support are directly targeted disabled individuals, whereas others are mediated through states or organizations. It is difficult to determine exactly which of these benefits are most relevant for the final study population of this paper. Also, the needs of each Down syndrome young adult might differ depending on the level of self-sufficiency and/or ongoing treatment of health conditions. Less self-sufficiency and severe health problems would be likely to yield more support. However for those of these initiatives that for example supports employment opportunities for disabled young adults, it might be the case that those young adults with the highest level of functioning are those whom are most likely to benefit.

Finally, on a geographical note, Western Australia is the largest state in Australia in terms of land area, occupying nearly one-third of the continent. In 2005 the population was 2.0 million, with the majority (1.5 million) residing in Perth which is the main city of the region.

5. Data and Sample

The number of available datasets on persons living with Down syndrome is very limited. The data used in this study comes from the NOW (Needs Opinions Wishes) questionnaire, which is a population-based study, focusing on the health, needs, and

function level of children and young adults with Down syndrome in Western Australia³. All phases of the data collection were conducted by researchers from the Telethon Institute for Child Health Research in the period 2004 to 2005. The data used in this paper are a product of a mailed survey distributed to parents and primary caregivers of children with Down syndrome age birth to 25 years residing in Western Australia. Potential participants were identified through the Western Australian government's birth registry and records from the Western Australian Disability Commission. The survey-instrument was distributed to the whole population of 500 families identified having a Down syndrome child. Of these 500, 363 (73%) returned the questionnaire. The focus of this paper is transition to adulthood and therefore only those cases when the Down syndrome child is age 16 to 25 (born 1980-1990), has been selected for analysis. In the original dataset this age-category included 128 cases. However, some of the respondents only filled out a reduced version of the questionnaire. The reduced version of the questionnaire was done out by respondents that did not return the mailed questionnaire, but whom were reached by phone and provided answers that way. In order to have as complete information as possible on all cases, only those 109 cases age 16 to 25 that filled out the full questionnaire are considered respondents and are included in the analysis. This final study population includes 109 cases and is considered the whole population (minus non-respondents) of Down syndrome young adults age 16 to 25 in Western Australia.

³ Great thanks to the researchers at the Telethon Institute for Child Health Research for making these data available. Indeed to Dr. Helen Leonard, Dr. Jenny Bourke and Dr. Ami Bebbington for their valuable help and suggestions.

It can be debated what is the correct age span in which to investigate the transition to adult life. The argument for choosing age 16 as the lower cut-off point here is the fact that schooling in Australia starts with a preparatory year followed by 11 years of primary and secondary school. By the end of the last school year the usual age of a child is 16 years, and it is expected that in the period that the child will find some alternative arrangement, such as continued learning, vocational training, or employment. The upper boundary of the age span is 25 years of age due to the fact that this the upper boundary of the original population to which the survey-instrument was distributed. Also, by that time (age 25) it must be expected that some sort of initial transition has occurred, - even if it has been delayed by the nature of the genetic disorder. In Table 3 an overview of individual characteristics and household description of the young adults in the final study population is presented⁴.

Table 3: Characteristics and Household Description of Down Syndrome Adolescents Age 16 to 25 in Western Australia, 2004-2005 (N = 109)

Characteristics	Number of cases	Percentage of final study population
<i>Gender</i>		
Male	63	58
Female	46	42
<i>*Presence of adults in the household</i>		
One adult	15	14
Two adults	94	86
<i>Household Income</i>		
Low	32	29
High	77	71

*Not including adult siblings

⁴ For further details about these variables see Appendix 2.

Table 3 Shows that there are overall fewer females in the final study population than there are males (46 females and 63 males), which corresponds to the fact noted by the Birth Defect Registry; that birth defects are more common in male infants than female infants (Birth Defect Registry 2006:7). Most of the Down syndrome young adults lives in an household where two adults are present (94%), and finally, the majority (71%) of the cases come from a family having high income.

6. Variables

In this study successful transition to adult life is specified as being in paid employment. The independent variables included in the subsequent analyses describe family resources, individual characteristics, as well as demographic information.

6.1 Employment

In the final study population 51% percent of the respondents are employed. However the intensity of the employment differs greatly among the Down syndrome young adults with regard to number of hours worked and whether the Down syndrome person holds one or more different jobs. For this reason the dependent variable of employment has been created as a three category ordinal variable. The three categories are unemployed, employed low intensity and employed high intensity. The employed low intensity includes Down syndrome young adults that are working less than 20 hours per week (part-time) in the same job. The employed high intensity includes Down syndrome young adults that are working 20 hours or more a week (full-time) and/or is working more than one job. As shown in Table 4, 28% of the final study population is in employed in high intensity and 24% is employed low intensity. It is important to stress that the label

'intensity does not refer to the type of job that the young adults hold, but reflects the amount of hours worked and the number of different jobs held. The reason for creating this distinction between high versus low intensity, is that the more hours worked or different jobs held, the higher level of participation and societal adaptation are present. It should be added that the types of jobs employed Down syndrome young adults hold are very similar (most often being helping hand in either a kitchen or at a grocery store), and therefore the job intensity becomes the important level of distinction.

Table 4: *Employment Status. Down Syndrome Adolescents Age 16 to 25 in Western Australia, 2004-2005 (N = 109)*

Characteristics	Number of cases	Percentage
<i>Employment</i>		
Employed, -high intensity/complexity	30	28
Employed, -low intensity/complexity	26	24
Unemployed	53	49
<i>Overall</i>	109	100*

* equals 101 due to rounding

The statistical analyses carried out in this paper allow for identification of causal relationships between combinations of family resources and employment outcomes, as well as the impact from individual characteristics and employment outcomes. Identifying such associations and confirming the direction of these, will contribute to an improved understanding of the conditions under which Down syndrome young adults transition to adulthood in general, and which of the below presented factors (if any) determines the

level of employment Down syndrome young adults obtain in particular. A description of the coding procedure of the initial independent variables included in the statistical analyses is provided in Appendix 2. In the remaining of this section the independent variables are described as well as the arguments for their inclusion.

6.2 Family resources

Nine variables are used to describe the potential family⁵ resources, all of which have been recoded into binary variables. The focus of this study is to review the impact of different resources, which are either present or not, or which is present to a high or a low degree. Coding the potential family resources as binary variables enables a more direct distinction, as well as a more straight forward interpretation.

6.2.1 Parental Health and Presence of Adults

The first of the nine family resource variables is parental health. To evaluate parental health the SF-12 - version 2 was used. SF-12 is widely used and accepted generic measure of health status that covers the areas of physical functioning, pain, health, vitality, social functioning, and mental health. The SF-12 has most recently been validated in the Australian context by Sanderson et al (2002). In the final study population 21% falls into the category of poor parental health and 79% are to be found in the category of good parental health. The second variable is the presence of two adults. Previous studies in the US has found that disabled children with mobility, self-care, communication, or learning limitations are less likely to live in homes with 2 parents

⁵ *Families* are two or more persons, living in a household, related by blood, marriage or adoption. All persons living in a household related to each other are regarded as one family. In this study the definition of household and family is used almost interchangeably, though one could easily have a household, where none or only some of the members were related in any familiar way.

present, and more frequently lived in single-parent and other arrangements (Wells et. al. 2003). Though, the aim of this study is not to compare the situation of the Down syndrome children in Western Australia to the greater general population of Australia or other nations, but the presence of parents or partners in the household, is here – in line with previous research – viewed as a resource. The majority (86%) of the final study population has two adults present. The expectation in this study is that living in a household with at least one healthy parent/primary caregiver and the presence of two adults will be positively associated with being in paid employment.

6.2.2 Parental Work Status, Skills, and Education

The third variable is parental employment status. Having at least one parent who is currently employed is viewed as a resource while it yields closer ties to a working environment, where the working parent(s) might have access to potential employment opportunities for their kids in general. In the final study sample 89% have at least one parent working. Access to employment opportunities for one's children through own employment is closely linked to what skill level is required. Down syndrome young adults will most often be employed in low skill jobs, and it is assumed that the skill level of the parents then matter with regard to access to potential employment opportunities. The fourth and fifth variable describes the skill levels of the mothers and fathers of the Down syndrome young adults. In the final study population 61% have mothers with high occupational skills and 50% had fathers with high occupational skills. Mothers and fathers skill levels correlate low to moderately on a 0.20 level. Finally, Parental education is also included in the analysis. The sixth and seventh variable describes mothers and

fathers educational attainment level. In the final study population 54% have mothers with high education, and 64% have fathers with high education, and mothers and fathers education levels correlate moderately on a 0.35 level. In general parent's education has been shown to be a powerful predictor of children's' outcomes - lower levels of parental education are associated with lower expectations of a child's relative educational and occupational achievements. In this study it is expected that parental education will work as a facilitator for understanding and navigate the complex social support system and push for opportunities for their child that exists in Western Australia today, and therefore to some degree be positively associated with the employment outcome of the Down syndrome young adults. However, the support and opportunities educated parents would push for will not necessarily be paid employment, but could as well be recreational therapies of various kinds.

6.2.3 Income and Financial Stress

The monetary resources available to the household are included both as a direct measure of combined income, as well as a more indirect measure of the parents feeling of financial stress. In the final study population 71% of the Down syndrome young adults are living in households reporting high income, and 72% is categorized as living in a household with a low financial stress. Both combined income and the level of financial stress is expected to contribute positively to the likelihood of the Down syndrome young adult to be I paid employment (keep in mind that as a resource high financial stress is 0 and low financial stress is 1).

6.3 Abilities and Health

The abilities to complete essential daily tasks independently are crucial for a person's everyday functioning. Abilities of the Down syndrome young adults in this study are measured using the Functional Independence Measure, also known as WeeFim. The WeeFim instrument measures consistent performance in essential daily functional skills through the assessment of three subscales each measuring different types of abilities. The variables of self-care, mobility and cognition are these three subscales, and are directly available as continuous variables in the data. On the WeeFim a higher score means the greater is the child's ability to complete the essential daily tasks without parental assistance or supervision.

In general health can be expressed as episodes of illness. Of course illness differs in severity and some types of illness would be more directly linked to the capability to maintain a job than others. For this reason a binary variable describing the number of times the young adult with Down syndrome had any medical care that involved overnight stays in hospital since January 1st 2004 has been created. Among the Down syndrome young adults 10% have had hospital overnight stays⁶.

In sum the level of abilities of the individual Down syndrome young adult are expected to have positive impact on being in paid employment, - understood as higher scores on each of the ability measure yield a higher likelihood of being employed. Health is expected to

⁶ Episodes of illness as well as short and/or long doctor's visits were also explored as measures of health. No matter which one is chosen the picture is the same as the one portrayed by using overnight stays in a hospital.

have a negative impact, - understood as no overnight stays in hospitals yield a higher likelihood of being employed.

6.3 Demographic variables

Age and sex is the demographic variables included in the model. As noted earlier, there is close to no variation on geographical location (ARIE), so this is not included in the model. The expectation is that the likelihood of being employed is positively related to age; while the longer you have been out of school the longer you have had to find one or more jobs.

6.5 Missing Values

Some of the variables had a small number of missing values. These have been imputed either by appropriate means for this population, or by the most reasonable estimate. Again, researchers Telethon Institute for Child Health Research, Western Australia have been very helpful in offering their expertise in this procedure. The income variable was the measure that suffered most strongly from missing values. 19 responded that they preferred not to answer and 11 did not answer the question of income at all. It was determined that the most suitable way to proceed was to code all of these 30 respondents as having high income. After preliminary analyses it was concluded that this was the best way to proceed.

7. Research Question and Hypotheses

The general research question driving this study is what kind of factors related to family life and individual capabilities affect the employment outcome for Down syndrome

young adults residing in Western Australia. In addition several hypotheses have been outlined when describing the independent variables. These hypotheses are summarized here:

Hypothesis 1: An overall higher level of resources available in the household, in which the Down syndrome young adult lives, will be positively associated with being in paid employment.

Hypothesis 2: Having a higher level of abilities will be positively associated with being in paid employment.

Hypothesis 3: Being in good health (have had no overnight stays in hospital) will be positively associated with being in paid employment.

Hypothesis 4: Age will be positively associated with being in paid employment

8. Method and Analyses

The statistical analyses are conducted in three stages. First, the variables describing family resources were used to create four family typologies. Second, descriptive statistics of family resources and individual characteristics of the Down syndrome adolescents is discussed. Third, logistic regression is used to determine what factors facilitate Down syndrome young adults to be involved in paid employment.

8.1 Stage 1: Latent Class Cluster Analysis

The family is the most important institution in providing care and support for a child. The key role of the family is to provide a positive resourceful environment through out the various stages of development in order to ensure successful transitions of its children. In this first stage latent class cluster analysis (LCA) is used to create typologies of the Down syndrome young adult families based on the nine binary variables describing the potential family resources. These typologies enable us to view the family as an environment where combinations of resources are at play simultaneously. Also, they allow us to work with a more parsimonious model and to improve the measurement of underlying concepts.

Basically latent classes are unobservable (latent) subgroups or segments, and LCA is the statistical method for finding such subgroups of related cases. The advantages of LCA over more traditional ad-hoc types of cluster analysis methods include model selection criteria and probability-based classification (Statistical innovations 2005:3). This means that although each object is assumed to belong to one cluster or class, it is taken into account that there is some uncertainty about an objects class membership. LCA is very flexible while both simple and complicated distributional forms can be used for the observed variables within the same clusters. The basic LCA model equation has the following form⁷:

$$f(\mathbf{y}_i|\theta) = \sum_{k=1}^K \pi_k f_k(\mathbf{y}_i|\theta_k).$$

Here, \mathbf{y}_i denotes an object's scores on a set of observed variables, K is the number of clusters, and π_k denotes the prior probability of belonging to latent class or cluster k or,

⁷ Formula and explanation is taken directly from Vermunt 'No year':2.

equivalently, the size of cluster k . Alternative labels for the y 's are indicators, dependent variables, outcome variables, outputs, endogenous variables, or items. As can be seen, the distribution of y_i given the model parameters θ , $f(y_i | \theta)$ is assumed to be a mixture of class specific densities, $f_k(y_i | \theta_k)$

In this study LatentGold® software was used to run the LCA, while this software are capable of managing all types of observed variables regardless of their scaling, and therefore also works well with the binary variables from this study.

The results from the LCA analysis suggested either a three or a four cluster model would be a good fit⁸ for the data describing the potential family resources available to the Down syndrome young adults. In principal a three cluster model is stated as a better fit by the software compared the four cluster model when evaluating the reported Bayesian information Criterion (BIC)⁹. However, BIC can sometimes ‘over-smoothen’ the data and punish the model too much for modeling additional clusters. For this reason AIC (An Information Criterion – Akaike 1974) statistic should also be reviewed. The AIC for the four cluster model is 1113.2 and for the three cluster model it is 1116.5. So the AIC tells us that the models are close to each other in fit, but that the four cluster model is a slightly better fit. The suggested LCA clusters can be interpreted as family typologies. The four cluster model for fits the theoretical interests of this paper very well, in that it includes a fourth family type that has fewer resources (Low resource family) available

⁸ Although there is no definitive way of statistically decide an optimal number of clusters while it is as noted also partly a theoretical decision, the Bayesian Information Criterion (BIC) provides a good indicator (Laub et. Al. 1998) and is the most popular. However AIC should also be reviewed.

⁹ The difference in model fit between a three and a four cluster model was relative small (~ 24) compared to the overall reported BIC level (~ 1200). For both BIC and AIC a smaller number yields a better fit.

compared. A primary focus of in this study is exactly to investigate resource availability and therefore differentiating between as many reasonable levels of resources availability as possible, would be the optimal way to go. Based on the fact that including the fourth family type adds substantial information and fits the theoretical interests of this study the best, and that the AIC statistic supports this number of clusters, the four cluster model is chosen.

In Table 5 the profile from the four cluster LCA run in LatentGold® is presented. This profile basically provides us with information on how each cluster has been differentiated. For example there can be a majority of cases with only one adult present in a particular cluster, but that does not necessarily means that the presence of one adult only (presence of two adults = 0) was a salient enough feature to form a cluster, i.e. strong enough to differentiate to qualify for an individual cluster distinction. The four family types are labeled 'Working class family', 'Middle class family', 'Stressed middle class family', and 'Low resource family'. A table describing the distribution among the nine variables included in the analysis within each of the four family typologies is provided in Table 6

8.1.1 Profile of Family Typologies

Working class family

In this cluster there are two adults present, the parent/primary caregiver answering the survey is in good health, and at least one of the parents is working. Both the father and

the mother of the Down syndrome young adult have low education and low occupational skills. The combined household income is high and the feeling of financial stress is low. 35% of the Down syndrome young adults live in this kind of family.

Table 5: Profile of Family Typologies from Latent Cluster Analysis. Down Syndrome Adolescents Age 16 to 25 in Western Australia, 2004-2005 (N = 109)

	Working class family	Middle class family	Stressed middle class family	Low resource family
<i>Cluster size</i>	34.9	33.0	17.4	14.7
<i>Indicators</i>				
Presence of two adults				
No	0.064	0.049	0.423	0.119
Yes	0.936	0.951	0.577	0.881
Parental Health				
Poor	0.117	0.0260	0.396	0.583
Good	0.883	0.9140	0.604	0.417
At least one parent working				
No	0.001	0.051	0.002	0.676
Yes	0.999	0.949	0.998	0.324
Fathers occupational skills				
Low	0.900	0.470	0.130	0.012
High	0.100	0.530	0.870	0.988
Mothers occupational skills				
Low	0.540	0.349	0.452	0.008
High	0.460	0.651	0.548	0.992
Mothers education level				
Low	0.608	0.070	0.525	0.736
High	0.392	0.930	0.475	0.264
Fathers education level				
Low	0.616	0.020	0.169	0.589
High	0.384	0.980	0.831	0.411
Combined income				
Low	0.261	0.005	0.518	0.650
High	0.739	0.995	0.482	0.350
Feeling of financial stress				
High	0.214	0.179	0.668	0.222
Low	0.786	0.821	0.332	0.778

Middle class family

In this cluster there are two adults present, the parent/primary caregiver answering the survey is in good health, and at least one of the parents is working. Both the father and

the mother of the Down syndrome young adult have high education and high occupational skills. The combined household income is high and the feeling of financial stress is low. 28% of the Down syndrome young adults live in this kind of family.

Stressed middle class family

In this cluster there are two adults present, the parent/primary caregiver answering the survey is in good health, and at least one of the parents is working. The father has high education and high occupational skills, and the mother has high occupational skills but low education. The family has low income and high financial stress. 19% of the Down syndrome young adults live in this kind of family.

Low resource family

In this cluster there are two adults present, the parent/primary caregiver answering the survey is in poor health, and at none of the parents is working. Both the father and the mother of the Down syndrome young adult have low education and high occupational skills. The family has low income and high financial stress. 14% of the Down syndrome young adults live in this kind of family.

8.1.2 Distribution of Resources by Family Type

Table 6 informs us further on the overall distribution within each of the included potential resources among the family types.

Adults Present and Parental Health

The majority of those families with only one adult present (13.8%) are to be found in the stressed middle-class family type (60 %). Whereas the remaining 3 family types each account for 13.3% of all the families that have only one adult present. The majority of the families that report to have two adults present (86.2%) is observed in the working class family type (38.3%) closely followed by the middleclass family type (36.2%) It should be stressed, that variable 'presence of two adults' was a salient enough feature to form a cluster distinction.

Out of the families that reported poor parental health (21.1%) a large part is in the low resource family type (43.5%). This family type also has the smallest percentage of cases reporting good parental health (7% of 78.9%). It is noticeable that there is no reporting of poor parental health in the middle class family type, and that this family type accounts for the largest part of the good parental health (41.9%).

Parental Work status, Skills, and Education

11% of the final study population has no parent working, and the majority of these cases are to be found in the low resource family type (83.3%). Both the working class family type and the middleclass family type have no incidents of not having at least one parent working. Out of the 89% of the final study population that reports having at least one parent working, 39.2% is in the working class family type , close followed by the middleclass family type that account for 35.1% of the cases where at least one parent is

employed. The low resource family is the family type that holds the least share of those having at least one parent working (6.2%).

Table 6: Distribution within the Variables Included in the Analysis among Each of the Four Family Typologies. Down Syndrome Adolescents Age 16 to 25 in Western Australia, 2004-2005 (N = 109)

	All (percentages)	Working class family (percentages)	Middle class family (percentages)	Stressed middle class family (percentages)	Low resource family (percentages)
<i>Cluster size</i>	100.0	34.9	33.0	17.4	14.7
Indicators					
Presence of two adults					
No	13.8	13.3	13.3	60.0	13.3
Yes	86.2	38.3	36.2	10.6	14.9
Parental Health					
Poor	21.1	26.1	0.0	30.4	43.5
Good	78.9	37.2	41.9	14.0	7.0
At least one parent working					
No	11.0	0.0	16.7	0.0	83.3
Yes	89.0	39.2	35.1	19.6	6.2
Fathers occupational skills					
Low	50.5	67.3	30.9	1.8	0.0
High	49.5	1.9	35.2	33.3	29.6
Mothers occupational skills					
Low	39.4	46.5	30.2	23.3	0.0
High	60.6	27.3	34.9	13.6	24.2
Mothers education level					
Low	45.9	50.0	4.0	20.0	26.0
High	54.1	22.0	57.6	15.3	5.1
Fathers education level					
Low	35.8	64.1	0.0	10.3	25.6
High	64.2	18.6	51.4	21.4	8.6
Combined income					
Low	29.4	34.4	0	31.2	34.4
High	70.6	35.1	46.7	11.7	6.5
Feeling of financial stress					
High	29.4	25.0	18.7	46.9	9.4
Low	70.6	39.0	39.0	5.1	16.9

The occupational skills of the fathers are in 50.5% of the cases classified as being low.

The large majority of these low skilled fathers are to be found in working class family type (67.3%), which is also the family type accounting for the least percentage of cases with fathers occupational skills being high (1.9% of 49.5%). Fathers with high

occupational skills are distributed fairly equally between the Middle class family type (35.2%), the stressed middle class family type (33.3%), and the low resource family type (29.6%).

Mothers occupational skills are reported low in 39.4 % of the cases and high in 60.6% of the cases. Almost half of the cases (46.5%) where mothers' skills are low are in the working class family type. There are no cases of mothers with low skills in the low resource families. The largest share (34.9%) of the highly skilled mothers is in the middle class family type, and the smallest share (13.6%) is in the stressed middle class family type.

Among the cases that reported low education for the mother (45.9%) the largest share of the cases (50%) are in the working class family type and the middle class family type has the least percentage (4.0%) of cases of mothers with low education. 54.1% of the mothers has high education. Among those the majority (57.6%) are in the working class family and the family type with the smallest share of the high educated mothers are low resource families (5.1%).

Fathers' education level is distributed in a similar manner to the mothers. However, more fathers have a high level of education (64.2%). The majority (64.1%) of fathers with low educational level are to be found in working class family type, and again the middle class has the least percentage of low education (0%). Among fathers with high education

51.4% is found in the middle class family type and the smallest share (8.6%) is found in the low resource family type.

Household Income and Financial Stress

In the final study sample 29.4% of the cases have low combined income and 70.6% has high combined income. Out of those with low income one of the cases are assigned to the middle class family type, and is distributed fairly even between the remaining three family types: working class family (34.4%), Low resource family (34.4%), and stressed middle class family (31.2%). The largest share (46.7%) of those families the reported high combined income is found in the middle class family type and the least share (6.5%) in the low resource family type.

Finally, 29.4% of the cases in the final study population reported high financial stress. Out of these cases the largest share is found in the stressed middle class family type, and the least share (9.4%) in the low resource family type. 70.6% was classified as having low financial stress, and the largest percentages of those are found in working class family type (39%) and in the middle class family type (39%). The smallest percentage (5.1%) is found in the stressed middle class family type.

The four family types described will be used as independent variables when explaining what family factors facilitate Down syndrome young adults to be in paid employment. Before moving to that analytical step, descriptive statistics allows for a review of the

characteristics of the Down syndrome young adults in the different employment categories.

8.2 Stage 2: Descriptive Statistics

In order to provide a clear overview of the distribution of the finalized variables included in the subsequent logistic regression analysis descriptive statistics are here provided. Table 7 summarizes the distribution of the Down syndrome young adults in the different employment categories with regard to family type, and presents group means of individual characteristics.

8.2.1 Results

Family types

The Down syndrome young adults living in a working-class family account for the largest share of the cases (34.9%) in the final study population. The majority (55.3%) Down syndrome young adults living in this type of family is unemployed, and almost an equal number of young adults are in each category of employment, meaning that 23.7% are employed in a low intensity job and 21.1% are employed in high intensity job(s).

In the middleclass family we find 33% of the Down syndrome young adults. A little less than half (47.2%) are employed. Of these 19.4% are employed in a low intensity job, and 33.3% are employed in high intensity job(s). 17.4% of the Down syndrome young adults live in stressed middle-class families. 47.4% of these are unemployed. Among the group of employed young adults living in this type of family 31.6% are employed in a low intensity job and 21.1% are employed in high intensity job(s).

Table 7: Resources. Descriptive Statistics. Down Syndrome Adolescents Age 16 to 25 in Western Australia, 2004-2005 (n = 109)

Characteristic	All (percentages) (N=109)	Unemployed (percentages) (N=53)	Employed - Low intensity (percentages) (N=26)	Employed - High intensity (percentages) (N=30)
<i>Type of family</i>				
Working-class family (N=38)	34.9	55.3	23.7	21.1
Middle-class family (N=36)	33.0	47.2	19.4	33.3
Stressed middle-class family (N=19)	17.4	47.4	31.6	21.1
Low resource family (N=16)	14.7	37.5	25.0	37.5
<i>Individual characteristics</i>				
Mean age in years	20	18	21	21
¶ Mean score - Self-care	50.4 (9.2)	47.5 (11.6)	52.3 (5.4)	53.9 (3.9)
¶ Mean score - Mobility	33.3 (3.3)	32.5 (4.4)	33.9 (1.5)	34.4 (1.1)
¶ Mean score - Cognition	37.6 (8.8)	34.8 (10.0)	40.2 (7.8)	40.1 (5.6)
Health (have had overnight stays in hospital)	10.1	45.5	27.3	27.3

¶ Note: what is written in () equals the standard deviation.

The same relative trend observed among the Down syndrome young adults living in middle-class families is apparent for the young adults living in low resource families. 14.7% Down syndrome young adults live in this type of family and 62.5% of them are in paid employment. 25% are working a low intensity job and 37.5% are working high intensity job(s).

Individual Characteristics

The mean age among the unemployed Down syndrome young adults are 18 years, which is 2 years lower than the overall mean of the final study population. The mean age among the employed Down syndrome young adults are 21 for both types of employment, which is 1 year higher than the overall mean for the final study population.

For all three of the ability measures (self-care, mobility and cognition) the mean among the employed Down syndrome young adults tend to be higher than for those unemployed. In all instances there are only little differences between the average of those employed in a low intensity job and those employed in high intensity job(s).

Finally, only a relative few of the Down syndrome young adults have had recent overnight stays in a hospital. Overall 10.1% of the 109 young adults in the final study population have had to spend the night in hospital. Among those who did experience to be in hospital overnight, 45.5% was unemployed, 27.3% employed in a low intensity job, and 27.3% employed in high intensity job(s).

In order to assess the likelihood of being employed the third and final stage of analysis – logistic regression is carried out.

8.3 Stage 3: Logistic Regression

In order to determine the factors facilitating employment two models are estimated using generalized ordered logistic regression, each focusing on and adding different types of resources. The equations for the logistic models estimated can be written as:

Model 1 – Family type

$$\ln(p/1-p) = \beta_0 + \beta_1 X_{\text{age}} + \beta_2 X_{\text{sex}} + \beta_3 X_{\text{Working-class family}} + \beta_4 X_{\text{Stressed middle-class family}} + \beta_5 X_{\text{Low resource stressed family}}$$

Model 2 – Family type, abilities and health (full model)

$$\ln(p/1-p) = \beta_0 + \beta_1 X_{\text{age}} + \beta_2 X_{\text{sex}} + \beta_3 X_{\text{Working-class family}} + \beta_4 X_{\text{Stressed middle-class family}} + \beta_5 X_{\text{Low resource stressed family}} + \beta_6 X_{\text{Self-care}} + \beta_7 X_{\text{Mobility}} + \beta_8 X_{\text{Cognition}} + \beta_9 X_{\text{Health}}$$

For all models $\ln(p/1-p)$ is the log odds of being employed, p is the probability of being employed, β_0 is the intercept, and β_{1-9} (β_{1-9}) is the matrixes of predicted log odds of being employed for the matrixes of covariates.

With regard to the dependent variable, the category of unemployed will serve as reference category in the generalized logistic regression models estimated. Among the

family typologies (included as independent dummy variables) the omitted family type is 'Middle class'.

8.3.1 Generalized Ordered Logistic Regression

One of the assumptions underlying ordinal logistic regression (ologit) is that the relationship between each pair of outcome groups is the same. In other words, ordinal logistic regression assumes that the coefficients that describe the relationship between, the lowest versus all higher categories of the response variable are the same as those that describe the relationship between the next lowest category and all higher categories. This is also called the proportional odds assumption (Williams 2005:1). The theoretical assumption in this study is that the coefficients that describe the relationship between the lowest category (unemployed) versus the all higher categories (employed low intensity + employed high intensity) of the response variable are *not* the same as the coefficients that describe the relationship between the lowest and the next lowest category (unemployed + employed low intensity) versus the highest category (employed high intensity). Therefore we employ general ordered logistic regression (gologit). General ordered logistic regression differs from ordered logistic regression, while it estimates regression models for ordinal dependent variables under the assumption that the relationship between all pairs of groups differ among the ordinal categories of the outcome variable¹⁰. The actual values taken on by the dependent variable are irrelevant except that larger values are assumed to correspond to "higher" outcomes (ibid). The generalized ordered logistic

¹⁰ Test of the proportional odds assumption was carried out using the 'omodel' command and 'brant' in stata. This test showed no significance (the proportional odds assumption was not being violated), which would usually lead to just go with the ordered logistic regression. However, due to the fact that we have few observations in some of the cells and that the test of the proportional odds assumption is based on chi2 tests, it is suspected to suffer from this and become less reliable. In addition, when running the models as generalized ordered logistic models we do find differences between the categories in the coefficients describing the relationships.

regression model relaxes the proportional odds assumption and allows the effects of the explanatory variables to vary with the point at which the categories of the dependent variable are dichotomized (Ibid).

8.3.2 Results

Table 8 presents the results of the generalized ordered logistic regression. As argued earlier the final study population captures the whole population, and therefore results are not interpreted with regard to statistical significance, but rather all relationships of substantial interest to the research question of this study are interpreted. The following interpretations of the findings when applying general ordered logistic regression is based on the second model (Model 2) that is considered the full model. Generalized ordered logistic regression can be interpreted in a similar manner to regular binary logistic models. In the case of this analysis the odds ratios in panel 1 can be interpreted in as unemployed versus employed low intensity + employed high intensity. Correspondingly, panel 2 can be interpreted as unemployed + employed low intensity versus employed high intensity. For all findings described below the interpretation assumes that all other variables in the model are held constant.

Family types

When reviewing the relationship between type of family and level of employment a very particular pattern becomes apparent in each of the panels. In Panel 1 we first observe that for a Down syndrome young adult living in a working-class family, as compared to a middle-class family, is 47% more likely to be working than to be unemployed. Yet, in Panel 2 we see the same Down syndrome young adult living in a working-class family, as compared to a middle-class family, is

Table 8: Odds Ratios. Generalized Ordered Logistic Regression Models. Down Syndrome Adolescents Age 16 to 25 in Western Australia, 2004-2005 (N = 109)

VARIABLES	<i>*Panel 1: Unemployed ('0') vs. employed low intensity + employed high intensity ('1')</i>		<i>*Panel 2: Unemployed + employed low intensity ('0') vs. employed high intensity ('1')</i>	
	MODEL 1	MODEL 2	MODEL 1	MODEL 2
<i>†Type of family</i>				
Working-class family	1.45	1.47	0.48	0.32
Stressed middle-class family	1.54	1.94	0.35	0.33
Low resource stressed family	1.22	2.20	0.90	0.66
<i>Abilities and Health</i>				
Self-care		1.07		1.16
Mobility		1.16		1.84
Cognition		1.01		0.90
Health (0= no overnight stays in hospital)		0.75		0.55
<i>Demographics</i>				
Age	1.55	1.60	1.23	1.27
Sex (0=male)	1.15	1.42	0.41	0.41

*The panels are read as binary logistic regression, hence the ('0') and ('1') in order to remind the reader of this

† The reference (omitted) category for family type is 'Middle-class family'

68% less likely to be working in high intensity employment than to be unemployed or working in low intensity employment.

If a Down syndrome young adult grows up in a stressed middle-class family, as compared to a middle class family, s/he is 94% more likely to work in either a low or high intensity job than to be unemployed. Again, in Panel 2 the same Down syndrome young adult living in a stressed middle-class family, as compared to a middle class family, is 67% less likely to work in high intensity/complexity employment than to be unemployed or to work in a low intensity job.

Similar direction of relationship is found when the Down syndrome young adult is living in low resource family. The likelihood of a Down syndrome young adult in a low resource family, as compared to a middle class family to be in any kind of paid employment is more than double versus being unemployed. In Panel 2 the same Down syndrome young adult is 34% less likely to be employed in a high intensity job, versus being unemployed or employed in a low intensity job.

In sum the results from the ordered logistic regression suggests that compared to the middle class family type all remaining three family types are more likely to be employed than to be unemployed. However, when it comes to distinguishing between what level of employment the young down syndrome young adults have, a reverse trend becomes clear. Compared to the middle class family type those young adults living in one of the three remaining types of families are less likely to be employed in high intensity job(s). These findings supports hypothesis 1 that

an overall higher level of resources available in the household, in which the Down syndrome young adult lives, will be positively associated with being in paid employment.

Abilities and health

In general the different types of abilities seem to have similar direction of their relationships with employment, but the strength of the relationships varies among the three different types of abilities. Panel 1 shows that for every unit increase in the score on the self-care measure the likelihood of being employed either in low or high intensity employment increases by 7%. For the mobility measure a similar positive relationship is observed, and the likelihood increase is 16% instead of 7% as seen for the self-care measure. In this panel also cognition seems to yield a positive relationship where every unit increase in the score on the cognition measure increases the likelihood of being employed either in low or high intensity employment with 1%. Regarding the health status of the Down syndrome young adult, Panel 1 shows that having had any recent overnight stays in a hospital decreases the likelihood of being in any kind of paid employment by 25%.

In Panel 2 it is observed that for each unit increase in score on the self-care measure, the likelihood of being in high intensity employment increases by 16%, compared to being unemployed or working in a low intensity job. A similar positive relationship is again observed for the mobility measure; however the strength of the relationship is stronger than for self-care. For every unit increase in score on the mobility measure the likelihood of being in high intensity employment increases by 84%, versus not working or working in a low intensity job. Finally a somewhat unexpected relationship is observed with regard to cognition. Each additional unit

increase in score on the cognition measure yields the Down syndrome young adult to be 10% less likely to be employed in a high intensity job versus being unemployed or employed in a low intensity job¹¹. Finally with regard to the health Panel 2 shows that if of the Down syndrome young adult has had any recent overnight stays in a hospital s/he is 45% less likely of being in high intensity employment versus being unemployed or working in a low intensity job.

In sum both for self-care and mobility we see that higher abilities are associated with greater likelihood of being employed compared to be unemployed. This trend is stronger when comparing being unemployed or being employed in low intensity job to be employed in high intensity job(s). Mobility had the strongest impact. These results for mobility and self-care leads to failing in rejecting hypothesis 2; that having a higher level of abilities is positively associated with being in paid employment. Yet, the measure of cognitive abilities does not lead us to the same conclusion. Also, the health of the Downs syndrome young adult also has an impact. The relationship between health and being in paid employment suggested that having had any overnight stays in hospital were negatively associated with being in paid employment, and thereby hypotheses 3 cannot be rejected.

Demographic information

Overall the likelihood of being employed is strongly age-graded. In Panel 1 it is shown that for each year of increase in age, the likelihood of Down syndrome young adults to be in any type of

¹¹ This is unexpected and it is difficult to find a reasonable argument that would support this finding. When exploring the measures and models it was tried to incorporate each of the 7 items included in the cognition measure separately. The argument for doing so stems from the fact that for example the ability of problem solving differs conceptually from the ability of social behavior and thereby can have different impact on the abilities required in employment. However there were no noticeable differences in the associations between each of the items and the overall measure of cognition. It is suspected that the finding could have something to do with the outcome variable and the fact that the tasks itself in the jobs held by the employed Down syndrome adults does not seem to differ very much with regard to cognitive demands.

employment increases by 60%. A similar association is found in Panel 2, however less strong. For every year of increase in age the likelihood of being in high intensity employment increases by 27% compared to being either unemployed or employed in a low intensity job.

With regard to sex Panel 1 shows that females are 42% more likely than males to in any type of paid employment than are males. However, Panel 2 shows that females are 59% less likely to be in high employment than are males. This tells us that females are probably most likely to be in working in low intensity/complexity jobs compared to males.

In sum it was hypothesized that age would be positively associated with being employed. The data analysis supports this expectation and thereby fails in rejecting the 4th hypothesis.

9 Conclusion

Parents of Down syndrome children face special challenges and unusual circumstances when planning for the future of their child. Each individual experiences a life with Down syndrome differently, which may yield different levels of expectations about the future, and about what independent adult roles Down syndrome young adults can take on. This study answers what kind of factors related to family life and individual characteristics affect the employment outcome for Down syndrome young adults residing in Western Australia.

Available resources in the family are an important factor when describing Down syndrome young adults entering into the labour force. The results in this study show that overall young adults from middle class families (highest resource availability) are less likely to be employed,

when the intensity level of the employment is not taking into account. Interestingly enough if when we adjust for level of employment intensity, these same young adults that are employed are more likely to be so in high intensity jobs, which signify higher levels of independency. Previous research often suggests parental education is positively associated with the expectations of a child's relative educational and occupational achievements. In this study the assumption was that high parental education would work as a facilitator for navigating the complex social support system related to have a disabled child. Therefore they would be more capable for creating better opportunities for their child. This in turn would be positively associated with the employment outcome of the Down syndrome child. However, the support and opportunities educated parents would push for would not necessarily be paid employment, but could as well alternative activities such as recreational therapies of various kinds. The results in this study speak very clearly to this expectation. If the high resource middle class parents can't find appropriate and full time employment for their child, they might be more prone to finding alternatives that would match the need of their Down syndrome child as well as their own expectations better.

In contrast, in working class, stressed middle class, or low resource families, where the parents may not be capable of navigating the social support system as well, the parents may have better access to social networks (e.g. through own low skilled employment) and thereby find an employment opportunity for their child of a low intensity nature.

Moreover, there seem to be a clear element of economic need present. Down syndrome young adults are in some instances contributing to the family income with earnings from their participation in paid employment. Stressed middle class and low resource families, are the family

types where the Down syndrome young adults are most likely to be in some kind of employment. The Down syndrome young adults living in low resource families, where none of the parents are working and the parent/primary caregiver report to be in poor health and the combined income is low, are more than double as likely to be in some kind of employment. The descriptive statistics show that among these low resource young adults that are employed, this group has the largest share working in high intensity jobs compared to the other three family types. Low resource families are considered having low income, but also report a feeling of low financial stress.

These findings suggest that researchers interested in the transition to adulthood for young adults with disabilities in general, and intellectual disabilities in particular, should not only focus on unitary measures of socio-economic status of the families. Instead they should look both at larger number potential human and socio-economic resources, as well as at the underlying combinations of these.

In addition, individual abilities matter for the young adults being in paid employment. It is not only the resources within the family that facilitate entry into the labor force. The level of individual abilities varies a lot among children with Down syndrome. This study shows that self-care (eating, grooming, bathing, and toileting related abilities) and mobility (transfer and movement related abilities) are crucial for the likelihood of Down syndrome young adults being in any paid employment, as well as having a powerful impact on the intensity level of this employment. Mobility is the more important of these two ability measures. The analysis might have been strengthened with an investigation of whether there is a threshold effect present understood as a level of abilities below which people can not be expected to obtain employment.

This would also have potential insights on how family advantages benefit low ability young adults compared to high ability young adults. However the number of cases in this study did not allow for further investigation of this issue.

Further research is needed on whether specific abilities under the umbrella of what is here labeled as self-care and mobility show a stronger relationship, or if it is rather particular combinations of these different single abilities. In addition, such studies might also profit from investigation of whether there is a threshold effect present. Threshold effect understood as a specific level of abilities below which people can not be expected to obtain employment. Such findings would yield potential insights on how family advantages benefit low ability young adults compared to high ability young adults. The number of cases in this study did not allow for such investigation.

So far most recent research on the transition to adulthood within groups of people with disabilities, has stressed the need to think more creatively of what types of actual outcomes can be expected for people with disabilities. This study has shown that careful consideration of the dependent variable should be of substantial interest too. The research for this paper has demonstrated the usefulness of incorporating the complexity involved in employment, rather than focusing on constructing alternative outcomes.

With regard to future research objectives for this particular study, a comparative study will be undertaken, including American data from the National Longitudinal Transition Study – 2 (NLTS2). In this dataset 125 Down syndrome young adults have been identified. Also, a

collaborate group has been established that are going to take on further investigation of the transition to adulthood for the Down syndrome children and young adults included in the original study population, by setting up an longitudinal study ideally following all 4 cohorts. a comparative study will be undertaken, including American data from the National Longitudinal Transition Study – 2 (NLTS2). In this dataset 125 Down syndrome young adults have been identified.

“A somewhat different journey - but different not necessarily negative. Lots more involvement with medical, allied health, etc. Lots more hassle with schools, lots more need to be conscious of planning ahead and negotiating”.

Mother of Down syndrome young adult when asked to comment on ways in which having a child with Down syndrome had affected her family.

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APPENDIX

APPENDIX 1: Overview of the Main Forms of Governmental Support for People with Disabilities in Australia

Income support (for example, the Disability Support Pension, Carer Payment, Carer Allowance (adult and child), Sickness Allowance, Mobility Allowance and Wife Pension)
Funding to organizations to provide employment services as well as the direct provision of employment and training programs
The provision of services and support through the Commonwealth Rehabilitation Service
The provision of funding to the States and Territories for accommodation support, respite, independent living and recreation services
Joint funding with the States for the Home and Community Care (HACC) Program
Funding to the States for administering aids and appliances schemes
Funding of organizations to provide advocacy, information and print disability services
Funding of organizations under the Continence Aids Assistance Scheme
Funding to sponsor industry projects
The provision of pharmaceutical and other medical benefits.

Source: <http://www.apf.gov.au/library/intguide/sp/disability.htm>

APPENDIX 2: Initial Variables Included in the Analysis

Variable	Description / Survey Question	Recoding procedure	Final variable type
Family Resources			
Parents' health	SF-12 - version 2. Battery of 12 questions for the respondent's self-assessment of personal health. Range of scores on the SF-12 runs from 0 to 100. A higher score yields better personal health.	The original continues variable was recoded into poor health (scores ≤ 50) and good health (scores > 50)	Binary: 0 = poor health and 1= good Health
Presence of 2 adults	Whether the respondent has a partner at present	-	Binary: 0 = no partner present and 1= partner present
Work status	Which of the following best describe mothers (fathers) current work status: 'not working due to child's disability', 'not working for other reasons', 'full time homemaker', 'looking for work outside home', and 'working full or part time (either outside the home or at a home-based business)'	After identifying the work status of the mother and father, this information was combined into one measure of whether at least one parent was working.	Binary: 0 = no working parent and 1= at least one working parent
Mothers' skills	Job title and description of main tasks	Both job title and occupational tasks were considered independently for each case. First they were coded one time, then a month later coded again with out reviewing the prior coding, and finally the coding was discussed between collaborators and a third final coding was made.	Binary: 0 = Mothers skills low and 1= Mothers skills high
Fathers' skills	Job title and description of main tasks		Binary: 0 = Fathers skills low and 1= Fathers skills high
Mothers' education	What is the highest qualification she has completed? 8 response options were given ranging from primary school to postgraduate degree.	For each of the two variables of mothers and fathers education the category of low education included primary school, some high school, and completed high school. Education beyond completed high school was considered high educational attainment.	Binary: 0 = Mothers education low and 1= Mothers education high
Fathers' education	What is the highest qualification he has completed? 8 response options were given ranging from primary school to postgraduate degree.		Binary: 0 = Fathers education low and 1= Fathers education high
Household income	What do you estimate the combined gross parental income (before tax) was in the 2003/2004 financial year, not including pensions? 8 response options were give ranging from 'less than \$20.800' to '\$78.000 or more' also including the category 'I prefer not to answer'.	The original variable was recoded into a binary variable of low and high income. Low income includes categories from less than 20.800 AUD to 41.599 AUD, and high income includes from 41.600 and up	Binary: 0 = low income and 1= high income
Financial stress	Which words best describe your family's money situation? 5 response categories were given 'we are spending more than we get', 'we have just enough money to get through to the next payday', 'There is some money left over each week but we just spend it', 'We can save a bit now and again', and 'We can save a lot.	This variable has been recoded so that 'we are spending more than we get', 'we have just enough money to get through to the next payday' is considered high financial stress and the remaining categories is considered low financial stress	Binary: 0 = low financial stress and 1= high financial stress

APPENDIX 2 - Continued: Initial Variables Included in the Analysis

Variable	Description / Survey Question	Recoding procedure	Final variable type
<i>¹²Abilities and Health</i>			
Self-care	Assesses the level of abilities of eating, grooming, bathing, dressing waist up, dressing waist down, indicating need to go to toilet, toileting, bladder management, and bowel management.	-	Continuous
Mobility	Assesses the level of abilities in doing chair transfers, toilet transfers, bath/shower transfers, general movement (walking), and going up and down stairs.	-	Continuous
Cognition	Assesses level of abilities with regard to comprehension, expression, everyday social interactions, control of behavior around others, problem solving, remembering recent events, and learning new skills and routines	-	Continuous
Health	number of times the young adult with Down syndrome had any medical care that involved overnight stays in hospital since January 1 st 2004	The original continues variable was recoded do no overnight admissions were coded 0 and having had any admissions were coded 1	Binary: 0 = No overnight admissions and 1= have had any overnight admissions
<i>Demographics</i>			
Age	What is your child's date of birth?	Calculated from date of birth of the Down syndrome young adult. Age is reported full years, and in the final study population it range from 16 to 25.	Continuous
Sex	What is your child's gender?	-	Binary: 0 = Male and 1= Female

¹² Abilities of the Down syndrome young adults are measured using the Functional Independence Measure, also know as WeeFim. The WeeFim instrument measures consistent performance in essential daily functional skills through the assessment of three subscales each measuring different types of abilities. The variables of self-care, mobility and cognition are these three subscales. On the WeeFim a higher the score means the greater is the child's ability to complete the essential daily tasks without parental assistance or supervision.

APPENDIX 3: Non-Numerical Presentation of Family Typologies

	Working class family (percentages)	Middle class family (percentages)	Stressed middle class family (percentages)	Low resource family (percentages)
<i>Indicators</i>				
Presence of two adults	Yes	Yes	Yes	Yes
Parental Health	Good	Good	Good	Poor
At least one parent working	Yes	Yes	Yes	No
Fathers occupational skills	Low	High	High	High
Mothers occupational skills	Low	High	High	High
Mothers education level	Low	High	Low	Low
Fathers education level	Low	High	High	Low
Combined income	High	High	Low	Low
Feeling of financial stress	Low	Low	High	High