EXTENDED ABSTRACT

"A somewhat different journey"

Living with Down syndrome: The transition to adult life for persons with Down syndrome

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Introduction

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. 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 the social and demographic factors, individual intellectual and personality characteristics of the adolescents, types of family functioning, and public policy interventions that as facilitators for young people with Down syndrome as they age from adolescents to adult life. A successful transition to adulthood in this context is understood as obtaining adequate degrees of self-sufficiency to live a relatively independent life. It should be noted that people with Down syndrome often differ significantly in their individual abilities, and this proposed study is focused on this difference within the group of people with Down syndrome and its possible interactions with other factors affecting the transition to adult roles. .

Significance

Since the early 1980s the life expectancy for people born with Down syndrome has increased remarkably. The two main reasons for this are: a) changes in access to primary healthcare, and b) advances in health technologies. 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 lead to that the greater majority of persons with Down syndrome grow up at home, where as up until a few decades ago these people would predominately have been placed in institutions. The changes in age composition and the regular inclusion in the family for persons with Down syndrome provide the basis for our research. This paper considers what available resources have significant effect on the person with Down syndrome to gain adequate levels self-sufficiency to live more independent adult lives. The goal is to present some of the most recent and unique data and insights to the trajectory of persons in their transitional stages living with Down syndrome.

Context

The data is collected among residents of Western Australia, which is a region that has experienced an increase in the proportion of prevalence of Down syndrome since the 1980s. As in many other regions of the world, despite relevant advances in prenatal care, Down syndrome is the single most common cause of intellectual disability in Western Australia.

Data

The available data is focusing on the health, needs, and function level of children and young adults age 0 to 25 with Down syndrome in Western Australia, together with extensive demographic information in their families. The data collection was conducted by researchers from the Telethon Institute for Child Health Research in the period 2004 to 2005. A survey was distributed to families and primary caregivers of with children with Down syndrome age 0 to 25 residin g in Western Australia. The parents or primary caregiver was asked to fill out a survey. Potential participants were identified through the Western Australian government's birth registry and records from the Western Australian Disability Commission. For the purpose of the study the survey-instrument was sent to the whole population[1]. The questionnaire was also made available online through the Telethon Institute's website. The participant population could access the questionnaire by a secure log-in. There were approximately 500 families identified with a Down syndrome child aged 25 years or under in 2004 (deceased and those with no contact details are not included in the 500 families). These families were sent a questionnaire. Of these 500 families, 363 returned the questionnaire, which yields a response rate of 73%. This paper considers persons in this population who are ages 16 to 25. This group includes 128 persons. Permission to use the data has been given from Telethon Institute for Child Health Research, and approval from the human subject committee (Brown University) was received on April 6th 2007.

Research question

The research question driving this study is what factors are related to strengthen the likelihood that young people with Down syndrome residing in Western Australia obtain adequate degrees of self-sufficiency to live a relative independent adult life. Exploring this research question further is an opportunity to learn about barriers and possibilities in the transitional stages of youth and adulthood for people with Down syndrome and the importance of taking on adult roles.

A general assumption in the literature on the transition to adult life is that there exists a positive relationship between parental socio-economic status and children's outcomes. An alternative hypothesis examined in this study is that in terms of work, fathers with unskilled occupations and those who live outside of major cities especially when they have good family and

[1] Theoretically it is possible to have a Down syndrome child that is not registered at any of the two places chosen to derive the population. Though, in practice the likelihood of such a situation is very small.

community support may be better connected to the type of jobs and support systems that would enable the young adult with Down syndrome to find appropriate employment. We also hypothesize that residence independent of the family will be more common in urban areas where there are more housing options available.

Dependent variable

Self-sufficiency can be associated with a broad variety of indicators, each related to different spheres of life. In this study the measures available are mainly restricted to employment and continued learning. With regard to employment the respondents were asked whether the child "is currently in paid employment or has been in paid employment within the last 12 months?" The answer categories to this question are yes/no. With regard to continued learning the respondents were asked to indicate if the child is still at school. Previous studies have shown that the type of self-sufficiency reflected by employment could be viewed as crucial and interlinked to the gaining of independence in other spheres of life. Though due to the nature of disabilities linked to living with Down syndrome, we wish to work with a concept providing a relatively high level of flexibility compared to what is usually used for measuring self-sufficiency related to transition to adulthood in the majority population. For this reason we will consider to include two additional measures. The first regarding whether the Down syndrome child resides in housing independent from their parent's home. The second accommodating the concern of taking into account the level of social engagement demonstrated by the child. When we look at persons with Down syndrome of the extended study population (age 0-25), the number of friends typically decreases as age increases (beginning from age 6). For those in our study population (age 16-25) that maintain a relatively high level of friends, or for whom the number of friends in fact is higher than from those younger (age 6-16), we consider as demonstrating high levels of social engagement.

In table 1 the study population is described by the main self-sufficient variables. With regard to employment and continued learning the distribution among males and females seem to be approximately equaled distributed. Half of the study population is working in paid employment outside the home (50.8%), and half of those are males (50.0%).

Table 1: Percent distribution of the study population by self-sufficiency variables

Self-sufficiency characteristics	Male	Female	Total
Employment			
Yes	50.0	51.9	50.8
No	50.0	48.1	49.2
Continued learning			
Yes	40.8	46.2	43.0
No	59.2	53.9	57.0

Distribution

A number of variables are hypothesized to be involved in determine self-sufficiency. The distributions of these variables in the study population are described in table 2, again with regard to the distribution among the two sexes. The overall picture shows us that there is only little variation between males and females in this account, with the most variation found in the variables describing the father's level of education and the child's usual place of residence. A slightly larger part of the females have a father with a high education level (8.2%). Also, more females than males reside in rural (17.1%).

Table 2: Percent distribution of the study population by basic background variables

Background characteristics	Male	Female	Total
Family composition			
Single child	5.3	13.5	8.6
Siblings	94.7	86.5	91.4
Presence of two adults	87.93	78.95	84.38
Presence of one adult	12.07	21.05	15.63
Family Income Level (AUS$)			
78,000 or more	18.4	13.5	16.4
41.600 – 77,999	19.7	25.0	21.9
20.800 – 41.599	11.8	15.4	13.3
Less than 20,800	17.1	15.4	16.4
Prefer not to answer	32.9	30.8	32.0
Parental education			
Father's education high	35.6	43.8	38.8
Father's education low	64.4	56.3	61.2
Mother's education high	32.0	38.3	34.4
Mother's education low	68.0	61.7	65.6
Parental occupation skill level			
Father's occupation skilled	56.6	55.8	56.3
Father's occupation unskilled	43.4	44.2	43.8
Mother's occupation skilled	76.3	73.1	75.0
Mother's occupation unskilled	23.7	26.9	25.0
Parental connection to labor force			
Father part of labor force	75.0	73.1	74.2
Father out of labor force	25.0	26.9	25.8
Mother part of labor force	59.2	63.5	60.9
Mother out of labor force	40.8	36.5	39.1
Place of residence			
Urban (high access)	92.1	75.0	85.2
Rural (remote)	7.9	25.0	14.8

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