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### Work outcome in young adults with disabilities

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# Work outcome in Young Adults with Disabilities

Anja Holwerda

# Work outcome in Young Adults with Disabilities

*ANJA HOLWERDA*

## *COLOFON*

This study was conducted within the Research Institute SHARE of the Graduate School of Medical Sciences, University Medical Center Groningen, University of Groningen and under the auspices of the research program Public Health Research (PHR).

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RIJKSUNIVERSITEIT GRONINGEN

**WORK OUTCOME IN YOUNG ADULTS WITH DISABILITIES**

Proefschrift

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Dit proefschrift draag ik op aan alle jongeren met een beperking, maar bovenal met mogelijkheden om mee te doen.

Ik wens jullie wijsheid en inzicht en de begeleiding en ondersteuning die jullie nodig hebben, zodat jullie voluit kunnen participeren op een manier die bij jullie past, zowel in werk als in het sociale leven.

*Aan Hem, die door de kracht die in ons werkt bij machte is oneindig veel meer te doen dan wij vragen of denken, aan Hem komt de eer toe.*

Efeze 3:20-21a



# CHAPTER 1

## General Introduction





## **BACKGROUND**

In the past decade the number of young people with disabilities has increased considerably (*Blomquist, 2006; Sleeboom et al., 2010*). This is partly the result of medical advances preserving life with more survivors with chronic and systemic diseases as a result (*Blomquist, 2006; WHO, 2010*). Advances in perinatal care have increased the number of premature babies who survive, resulting in more developmental and behavioral problems in childhood, increased special educational needs and more medical and social disabilities in adulthood (*Kerstjens et al., 2013; Moster et al., 2008*). Preterm births were also associated with lower educational attainment and receipt of disability benefits (*Moster et al., 2008*).

In European countries the percentage of young people with a disability or long-standing health problem is estimated to be 16% (*Eurofound, 2012; WHO & World Bank, 2011*). These young adults experience physical, mental and/or developmental disabilities and many experience limitations in their personal functioning resulting in limited participation in society. They are especially vulnerable during the transition from school to work, which is an important milestone in their transition to adulthood (*Lindsay, 2011*). Many of these young adults participate in special needs education and prepare for the labour market through vocational training and placements. However, only about 50% of them are competitively employed after leaving school (*Fabian, 2007; Wagner et al., 2005*). In general, young adults with disabilities are much less likely to be employed than non-disabled young people (*Findley & Sambamoorthi, 2004; Pascall & Hendey, 2004; Randolph, 2004*) and they experience considerably lower employment rates compared to their non-disabled peers (*Blomquist, 2006; Ireys et al., 1996; Lindsay, 2011; OECD, 2009; Randolph, 2004*). Moreover, their unemployment periods often last longer and they face higher risks of losing their jobs than non-disabled people (*www.edf-feph.org*).

To increase the employment rates of young disabled is a challenge from a personal as well as a societal perspective. In recent years the focus on disability has shifted from compensation of limited wage earning capacity by social security benefits to participation according to ability. Moreover, also from the perspective of health and quality of life it is important for young adults with disabilities to be active in the labour market (*WHO, 2001*). Many young adults with disabilities would like to work, just like their healthy peers, and prefer not to be dependent on welfare benefits (*Lindsay, 2011*).

## **STATE OF THE ART**

Knowledge regarding opportunities for young adults with disabilities to participate in work and factors that influence the realization of these opportunities in practice is hardly available. Few prognostic studies are available regarding predictors for work participation of these young adults. Some studies have been conducted in large disease specific populations, like individuals with a bipolar disorder (*McIntyre et al., 2006; Zimmerman*

*et al.*, 2010), severe mental illness (Cook *et al.*, 2007), musculoskeletal disorders (Waghorn *et al.*, 2006), and COPD (Kremer *et al.*, 2006). Up to now, no studies are available that focus on the group of young adults claiming disability benefits in general, irrespective of their disability.

In many European countries, a majority of young people with disabilities are diagnosed with mental health disorders. Mental health and psychosocial impairments are increasing in several European countries, especially amongst young people (Eurofound, 2012). The prevalence of developmental disorders, including intellectual disability, is estimated to be 14% (Boyle *et al.*, 2011). Developmental disorders are common and increasing, with autism spectrum disorders and attention deficit hyperactivity disorders showing the most significant and successive increases over time (Boyle *et al.*, 2011). The same applies to the Netherlands: of the group of young people with disabilities receiving a disability benefit, 38% has an intellectual disability, 28% has other developmental disorders, including autism spectrum disorders (ASD) and 21% has a psychiatric disorder as a primary diagnosis (UWV, 2011).

As a result of the interaction of health conditions, personal factors, and environmental factors, the experience of disability by individuals varies greatly (WHO & World Bank, 2011). Individuals with intellectual disabilities and developmental disorders are especially vulnerable. Research suggests that people with mental health conditions or intellectual disabilities may be more disadvantaged in many settings, including employment, than other disability groups (WHO & World Bank, 2011). It is well-established that individuals diagnosed with developmental disorders suffer from problems in daily life functioning and work participation is not self-evident for them (Barkley *et al.*, 2006; Boeltzig *et al.*, 2008; Burke *et al.*, 2010; Cimera & Cowan, 2009; De Graaf *et al.*, 2008; Frazier *et al.*, 2007; Gjervan *et al.*, 2012; Halmoy *et al.*, 2009; Kuriyan *et al.*, 2013). The participation rates of young adults with intellectual disabilities (ID) range from 10% to 40% (Ireys *et al.*, 1996; Lysaght *et al.*, 2012b; Rose *et al.*, 2005; WHO & World Bank, 2011) and the participation rates of those with ASD and ADHD from 10% to 50% (Barkley *et al.*, 2006; Billstedt *et al.*, 2005; Engstrom *et al.*, 2003; Gjervan *et al.*, 2012; Halmoy *et al.*, 2009; Shattuck *et al.*, 2012; Wagner *et al.*, 2005). These employment rates are considerably lower than the employment rate in the general population which exceeds 65% in most developed countries (Lysaght *et al.*, 2012b). Moreover, many individuals with intellectual and developmental disorders desire to participate in work (Donnelly *et al.*, 2010; Eggleton *et al.*, 1999; Lindsay, 2011), which provides them with opportunities for financial independence and independent living, as well as a structured life and meaningful social participation (Dixon *et al.*, 2001; Eggleton *et al.*, 1999; Grant, 2008; Jahoda *et al.*, 2008; Lysaght *et al.*, 2012a; 2012b; Stephens *et al.*, 2005). Furthermore, work participation is considered to be an increasingly important health outcome (WHO, 2001).

Because of the limited participation rates, for many young adults with disabilities social security benefits can be a 'safety net' for the financial consequences of disability. Several European countries as well as the US have legislation regarding benefits for individuals with disabilities, for those able to work as well as for those not able to work. In the majority of European countries an increase in disability-related income support and benefits granted to young people was noted (*Eurofound, 2012; www.apa.org; www.disability-europe.net*).

### **THE DISABILITY CLAIM ASSESSMENT IN DUTCH CONTEXT**

In the Netherlands, young adults with congenital disabilities or those that originated during childhood (before 18 years of age) can apply for a disability benefit at the Social Security Institute (SSI) based on the so-called 'Invalidity Insurance Act for Young Disabled Persons' (in Dutch: Wajong). This benefit is not obligatory or automatically including all young adults with disabilities: the initiative for application lies with the individual and his/her social environment. This Invalidity Insurance Act for Young Disabled Persons provides (supplementary) income support as well as support to find employment and if necessary support at the work place. The insurance physician (IP) of the SSI is responsible for the assessment of work limitations and abilities of the claimants. In the disability claim assessment practice the level of work ability is determined by estimating the claimants' chances to find and retain employment independently, earning at least minimum wage level, and by assessing their need for assistance and support (*UWV, 2008*). The majority of the Wajong recipients is potentially (partially) capable to work (87%). The other part is declared fully unfit for work (13%) (*UWV, 2011*); they receive a disability benefit until their 65th birthday. Wajong recipients who are potentially (partially) capable to work are referred to the labour expert of the SSI. The labour expert assesses education and skills of the young adult and searches for suitable job profiles that might fit the young adult. Young adults with (very) limited abilities to work are referred to sheltered employment workshops. Young adults with the ability to work in competitive employment are subsequently referred to a reintegration consultancy for further training, if necessary, and job placement. Next to the disability benefit that supplements their income from work, the SSI also provides services and facilities to the young adult on the job, like job coaching. Despite the considerable efforts to support young people with disabilities in the Netherlands to find and maintain employment, still only 25% of those who have been granted a disability benefit participates in work and this percentage has been stable for years (*UWV, 2012*).

### **THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING**

As disability is complex, dynamic and multidimensional, the "medical model" for framing disability does no longer suffice. Disease specific factors are only partly able to explain work outcome and personal and social environmental factors are needed to create a complete picture.

The model that is used as underlying framework for the Dutch disability claim assessment is the WHO's International Classification of Functioning (ICF) model (WHO, 2001). The ICF describes functioning and disability as a dynamic interaction between health conditions and contextual factors, personal as well as environmental (see figure 1) (WHO & World Bank, 2011). The ICF-model stipulates that functioning encompasses mutually related components: disease and disorder, body functions and structures, activities, participation, and personal and environmental factors. Functioning can be classified from three different perspectives: the perspective of the body (body functions and structure), the perspective of the individual (personal activities), and the perspective of society (participation) (Heerkens et al., 2004). The model states that disease can lead to loss in abilities, which in turn can lead to problems in participation in society. The functioning (both the capacity and the performance) of the individual can be influenced by the disease or disorder, but also by personal factors (e.g. age, gender, self-esteem and motivation) and by environmental factors (e.g. the social environment) (Heerkens et al., 2004). Disability involves dysfunction because of impairments, activity limitations and/or participation restrictions, influenced by personal and environmental factors.

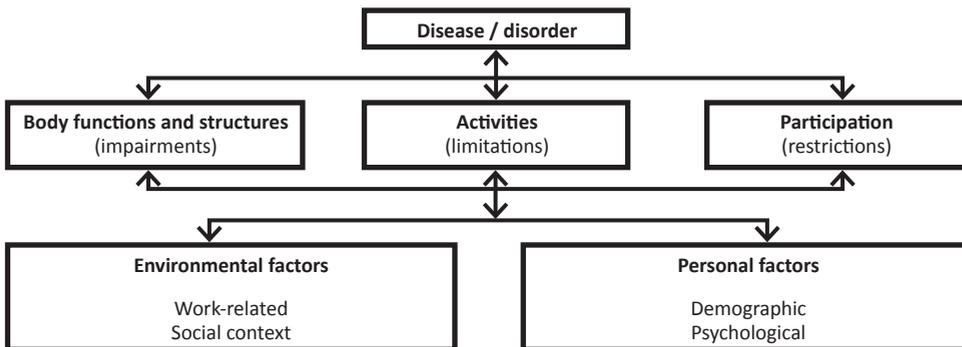


Figure 1 : Representation of the International Classification of Functioning, Disability and Health

Research suggests that personal factors, e.g. motivation, self-esteem and self-knowledge, influence whether individuals are able to utilize their ability to participate in work. The influence of motivation has been well established in the literature (Auerbach & Richardson, 2005; Foley et al., 2012; Linden et al., 2010; Rose et al., 2005; Stahl et al., 2011; Suzuki et al., 2008; Timmons et al., 2011). Self-esteem has been suggested to contribute to higher wage employment and career satisfaction over time (Lindstrom et al., 2011), while lack of self-esteem in individuals with disabilities has been found to decrease the chance of employment (Bassett et al., 2001; Corbiere et al., 2011; Eisenman, 2003). Furthermore, personal factors are frequently mentioned by professionals

working with individuals with disabilities as important predictors for work outcome. Next to personal factors, social environmental factors, e.g. family involvement and social support, often are essential in securing employment for individuals with disabilities (Eisenman, 2003; Foley et al., 2012; Timmons et al., 2011). Research highlights the influential role of significant others and social networks in mediating the employment success of young adults with disabilities (Carroll et al., 2009; Carroll & Dockrell, 2012; Eisenman, 2003; Hughes, 2001). The perceptions and support of a person's environment has an important impact on the experience and extent of disability of an individual (WHO & World Bank, 2011) and thus on the participation of that individual. Several studies suggest that parents can be a powerful influence on the employment options, experiences and outcomes of their young adult with disabilities (Cooney, 2002; Doren et al., 2012; Eisenman, 2003; Wagner et al., 2005). The supportive role of parents is important in the transition from school to work for individuals, offering career-related advice, emphasizing work-related goals, helping to find jobs, shaping aspirations and offering practical and moral support to maintain employment (Dixon & Reddacliff, 2001; Eisenman, 2003; Foley et al., 2012; Kirsh et al., 2009; Timmons et al., 2011).

Furthermore, school teachers are also said to substantially contribute to the educational achievements of young adults and the preparation of young adults for the workforce and play a critical role in their subsequent transition to employment (Kim & Dymond, 2010; Laragy, 2004; Oeseburg et al., 2010). However, the influence of significant others, like parents and school supervisors, can be positive as well as negative. Parents as well as school supervisors may stimulate, but also underestimate the abilities of young adults with disabilities (EADSNE, 2006). Underestimation hinders young adults in reaching their full potential. Despite the important role significant others are said to play in the transition from school to work of young adults with disabilities, little is known regarding the process and different aspects of this influence of significant others in the working lives of young adults with disabilities.

### **WORK OUTCOME**

Work participation consists of two elements, finding employment as well as maintaining employment. Many studies on work participation of young adults with disabilities focus on unemployment status (Paternite et al., 1999), number of jobs held (Barkley et al., 2006), percentage of job loss (Barkley et al., 2006) or occupational status (Dunham et al., 2000; Hansen et al., 1999; Kuriyan et al., 2013; Liptak et al., 2011; Martorell et al., 2008; Rose et al., 2005; Taylor & Seltzer, 2011). No studies on sustainability of employment, i.e. finding and maintaining a job for a specified period of time, in this population were found. Young people need sustainable social and work participation to develop their social and practical skills and to nurture their physical and psychological well-being (Lindsay, 2011).

Despite the different initiatives taken around the world, like the United Nations Convention on the Rights of Persons with Disabilities (2006) and the European Pact on the Equal Rights of Persons with Disabilities (2009) as well as different country policies to support young adults with disabilities to be included in the labour market, it is unclear what needs to be done to ensure increased work participation of individuals with disabilities.

### **OBJECTIVES OF THIS THESIS**

The objective of this thesis is to gain insight into the personal and social environmental factors predicting work participation, finding as well as maintaining employment, among young adults with disabilities applying for a disability benefit.

Two main research questions were formulated:

#### **Research question 1:**

Which personal and social environmental factors predict work participation of young adults with disabilities applying for a disability benefit?

#### **Research question 2:**

Do personal and social environmental predictors differ for disease-specific subgroups?

### **OUTLINE OF THIS THESIS**

Chapter 2 gives a description of the design of the study.

In chapter 3 a study is presented examining the factors associated with work-ability level among young adults with disabilities applying for disability benefits as assessed by the insurance physician of the Social Security Institute.

In chapter 4 the expectations of young adults with mental disabilities, their parents and their school teachers regarding future ability to work are described. Furthermore the ability of these young adults, their parents and their school supervisors to predict future work status is addressed and the most predictive perspective of work outcome after leaving school is identified.

In chapter 5 a systematic review of the literature is presented regarding facilitating or hindering predictors for work participation in individuals with autism spectrum disorders.

Chapter 6 presents the factors predicting work participation, finding as well as maintaining employment, of young adults with autism spectrum disorders and attention deficit disorders.

In chapter 7 the predictors of work participation of young adults with mild intellectual disabilities are described.

Chapter 8 provides a general discussion regarding the main findings of this thesis as well as its strengths, limitations and also its implications for policies and practices and directions for future research are discussed.

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# CHAPTER 2

## Study design and data sources





This chapter describes the design and methods of the “Young Disabled at Work” cohort-study, a longitudinal prospective study following young adults applying for a disability benefit for a two-year follow-up period. The preparations for this study started in 2007, a pilot-study was held in 2008, and data collection started in 2009.

### **POPULATION**

In our cohort study all young adults with disabilities applying for a disability benefit with the Social Security Institute (SSI) from January 1st to December 31st 2009 in the three northern provinces of the Netherlands, Groningen, Friesland and Drenthe, were eligible to participate in the study. Only young adults with disabilities were included of whom the insurance physician of the SSI had indicated that they did have an ability to work or for whom an ability to work could not be ruled out, based on the present disability status of the young disabled adult. Written consent was provided by all claimants and the Medical Ethics committee of the University Medical Center Groningen, the Netherlands, approved recruitment, consent and field procedures prior to the study.

### **QUESTIONNAIRE DEVELOPMENT – EXPLORING THE LITERATURE AND INVOLVING ACTORS IN THE FIELD**

In the first phase of the project (March to November 2008) factors relevant for finding and maintaining employment were explored, based on study of the literature and relevant policy documents, file research, and interviews with experts, employers and school supervisors in special needs education (*Achterberg, Holwerda et al., 2010*). The factors found were classified using the International Classification of Functioning, Disability and Health (ICF) model in disease-related, personal and social environmental factors (*WHO, 2001*) (see also Chapter 1).

Based on literature and the interviews, 31 factors expected to be associated with work participation were included in the cohort-study. These factors were classified as disease-specific factors (diagnosis, comorbidity, secondary conditions), personal factors (demographic, psychological) and environmental factors (work-related and social context-related) (see figure 2.1).

Because of the limited cognitive ability of part of the sample, it was not possible to use existing questionnaires. Therefore a questionnaire was developed using themes from the literature and items from other questionnaires which were adapted to be easily comprehensible. If needed, respondents could ask for help when filling out the questionnaire. To get a realistic picture of the young adult with disability, we chose a differential approach by asking participants from different perspectives (young adult with disability, parent, school teacher, insurance physician) to fill out questionnaires to provide information.

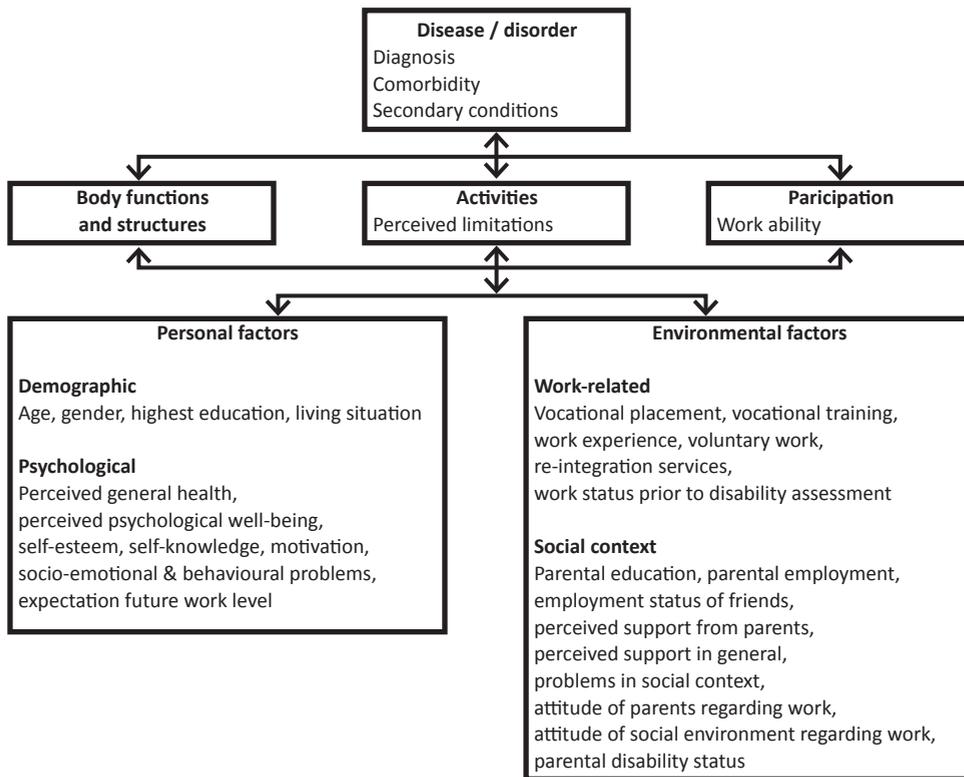


Figure 2.1: Factors included in the cohort study regarding young adults with disabilities classified according to the ICF-model

The questionnaire for the young adult with disability consisted of 90 items. The questionnaire for the parents consisted of 52 items and the questionnaire for the school teacher consisted of 62 items. These parent and school teacher questionnaires consisted mainly of items regarding the personal and social environmental characteristics of the young adult and had many items in common with the questionnaire for the young adult themselves. In the questionnaire for parents, also questions regarding educational level and work status of parents were included.

The questionnaire for insurance physicians was developed in cooperation with the insurance physicians of the SSI and consisted of 12 items regarding diagnosis, comorbidity, secondary conditions, work ability and the possible need for support to find and maintain employment.

## MEASURES

Demographic information was derived from the SSI-registers and linked to the data from the questionnaires. In table 2.1 the topics which were adopted from existing questionnaires are listed and the topics for which self-constructed questions were used.

Table 2.1: Overview topics, measures and informants at baseline

Topic	Measure	Informant
<b>Disease-specific factors</b>		
Diagnosis	CAS-code, derived from the ICD-10	Insurance physician
Co-morbidity	CAS-code, derived from the ICD-10	Insurance physician
Secondary conditions	Self-constructed	Insurance physician
<b>Personal factors</b>		
Age	Data Dutch Social Security Institute	
Gender	Data Dutch Social Security Institute	
Highest educational level	Adapted from question Dutch Social Security Institute	Young adult
Perceived general health	Youth Public Health Survey	Young adult
Perceived psychological well being	Youth Public Health Survey	Young adult
Perceived limitations	POLS Basic Questionnaire adapted from the POLS Youth questionnaire (Permanent Study of Living Situation)	Young adult
Work ability	Data Dutch Social Security Institute	Insurance physician
Self-esteem	Youth Public Health Survey	Young adult
Self-knowledge	TNO questionnaire <i>'Roadmap to work for adolescents with serious behavioural problems, investigation of successful guidance'</i>	Young adult
Motivation	Self-constructed	Young adult
Socio-emotional & behavioural problems	Self-constructed	Insurance physician
Expectation future work level	Self-constructed	Young adult, parent and school teacher
<b>Social environmental factors</b>		
Living situation	Tracking Adolescents' Individual Lives Survey (TRAILS) questionnaire T4Youth based on the National Monitor Youth Health in the Netherlands	Young adult
Perceived support from parents	Self-constructed	Young adult
Perceived support in general	Adapted from the POLS Youth questionnaire (Permanent Study of Living Situation)	Young adult
Attitude of parent regarding work	TNO questionnaire <i>'Roadmap to work for adolescents with serious behavioural problems, investigation of successful guidance'</i>	Young adult, parent and school teacher
Attitude of social environment regarding work	TNO questionnaire <i>'Roadmap to work for adolescents with serious behavioural problems, investigation of successful guidance'</i>	Young adult, parent and school teacher
Parental education	Questionnaire Occupational Care T4 (Arbozorg)	Parent
Parental employment	POLS Youth questionnaire (Permanent Study of Living Situation) (young adult) Youth Public Health Survey (parent)	Young adult, parent
Employment status of friends	Self-constructed	Young adult
Parental disability status	Self-constructed	Parent
Problems in social context	Self-constructed	Insurance physician
<b>Work-related environmental factors</b>		
Vocational placement	Self-constructed	Young adult
Voluntary work	Youth Public Health Survey	Young adult
Vocational training	Self-constructed	Young adult
Work experience	Self-constructed	Young adult
Re-integration services	Self-constructed	Young adult
Work status prior to disability assessment	Data Dutch Social Security Institute	

### **DATA COLLECTION AND PROCEDURE**

All eligible applicants for a disability benefit have been requested by the SSI to fill out a questionnaire before coming to the SSI for the disability claim assessment. Parents of young adults living at home with their parents were also asked to fill out a questionnaire. Furthermore, school teachers were asked to fill out a questionnaire when applicants attended special needs education. Applicants were requested to hand in the questionnaires when coming to the insurance physician of the SSI. When questionnaires were not filled out, the insurance physician gave a new questionnaire to the applicant with a return envelope and requested to fill out the questionnaire and send it to the SSI. The questionnaires were supplied with a respondent number and the data were supplied to the researcher anonymously. The paper questionnaires were stored in the SSI office. The follow-up started in the quarter following the final decision of the SSI regarding the disability benefit. Because the inclusion period lasted one year, the follow-up period per individual ranged from one year and three months to two years and nine months and ended at September 30, 2011 for all participants.

### **RESPONSE**

During the inclusion period 3455 people applied for a disability benefit in the three northern provinces of the Netherlands. Of these applicants, 2320 (67.1%) were granted a disability benefit. Register data from the SSI as well as the data for work outcome were available for the complete sample. The insurance physician of the SSI filled out a questionnaire for 2545 applicants (73.6%).

The response to the questionnaires for young adults with disabilities and their parents and school teachers varied considerable with the actor involved filling out the questionnaire. Of the young adults, 1966 (56.8%) filled out a questionnaire. These respondents did not differ from non-respondents with regard to gender, but did differ regarding age, diagnosis, disability status and work status. Respondents were younger, had more often a mild intellectual disability and less often a psychiatric disorder, respondents were more often granted a disability benefit, and respondents worked more often for at least six consecutive months. Therefore, the results of the analyses based on self-report are mainly applicable to young adults with disabilities below 27 years of age with intellectual and other developmental disorders, which is the focus of most articles in this thesis.

Of the parents involved, 1194 parents of young adults living at home with their parents filled out the questionnaire. Of the school supervisors involved, 450 school supervisors of young adults attending special needs education filled out a questionnaire. As we do not know which percentage of young adult applicants was still living at home or attended special needs education during the disability assessment procedure, the percentage of parents and school supervisors that responded is unknown.

## WORK PARTICIPATION

Work participation was defined as finding and maintaining employment. Finding work was defined as work at any point during the follow-up. Maintaining employment was defined as work for at least six consecutive months during the follow-up.

Both work outcome measures, finding work and maintaining employment, were derived from the POLIS register data. The POLIS registry is a database, in which all Dutch workers are included that have earned any wage (from regular, supported or sheltered jobs) and paid wage tax in the period concerned. Only paid work - for any number of hours - was included. Work related day activities or voluntary work are not included in this definition of work. The data were supplied anonymously (with respondent number only) to the researchers, who matched the data to the results of the questionnaires. In the period from December 2008 until September 2011 wage earning in the preceding month was assessed every quarter (twelve measurements). Only wage earning following disability claim assessment was taken into account.

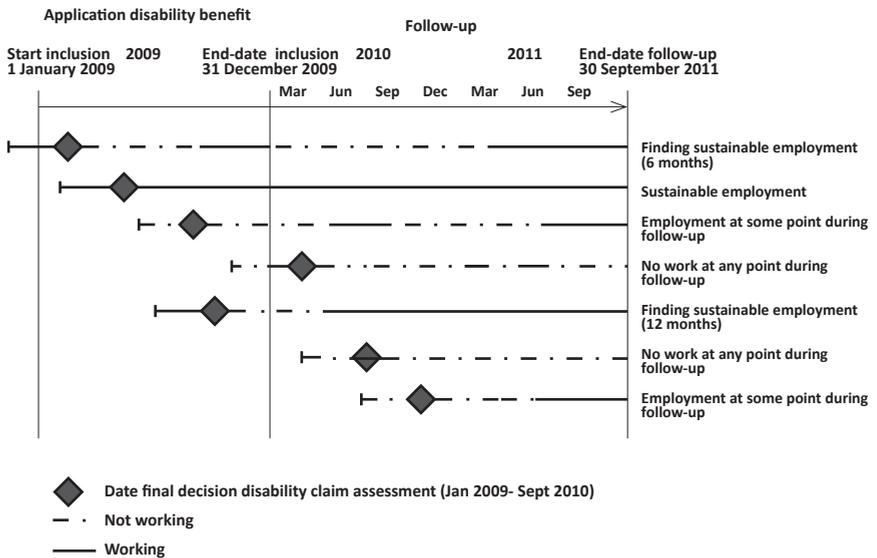


Figure 2.2 Flow diagram of possible work outcome of young adults with disabilities

### **STAKEHOLDERS INVOLVEMENT**

Our cohort study has been accomplished through cooperation with different stakeholders in the field of social security and special education and rehabilitation. The project was supported by the SSI in the Northern Netherlands and the council of special needs education schools in the Northern Netherlands. The existing network with the special needs education schools made it possible to guarantee the contribution of these schools to the study and to disseminate the results for their benefit. To inform the parties concerned, the researcher regularly attended meetings of directors and school supervisors of special needs education. Furthermore, the researcher also attended meetings of networks around young adults with disabilities in their transition from school to work, in which the social security institute, special needs education, reintegration agencies and other support agencies were represented. A regional committee was established to create a support base within the institutes involved in the project and to support the implementation of the results of the study. In this committee the social security institute, special needs education, employers, sheltered workshops and the municipalities involved were represented. To inform all parties involved regarding the results of the cohort study, the results of the study have been presented at a symposium specifically organized for this purpose and attended by approximately 500 participants from the different institutes involved in the study.

### **STATISTICAL ANALYSIS**

Several statistical methods were used across this study in order to analyse the data. In general, analyses were performed with the statistical software package in PASW Statistics 18.0.3 (SPSS) (chapter 3 and 4), the multilevel ordinal logistic analyses were conducted in STATA 11.2 (chapter 3) and the survival analyses in STATA version 12.1 (chapter 6 and 7).

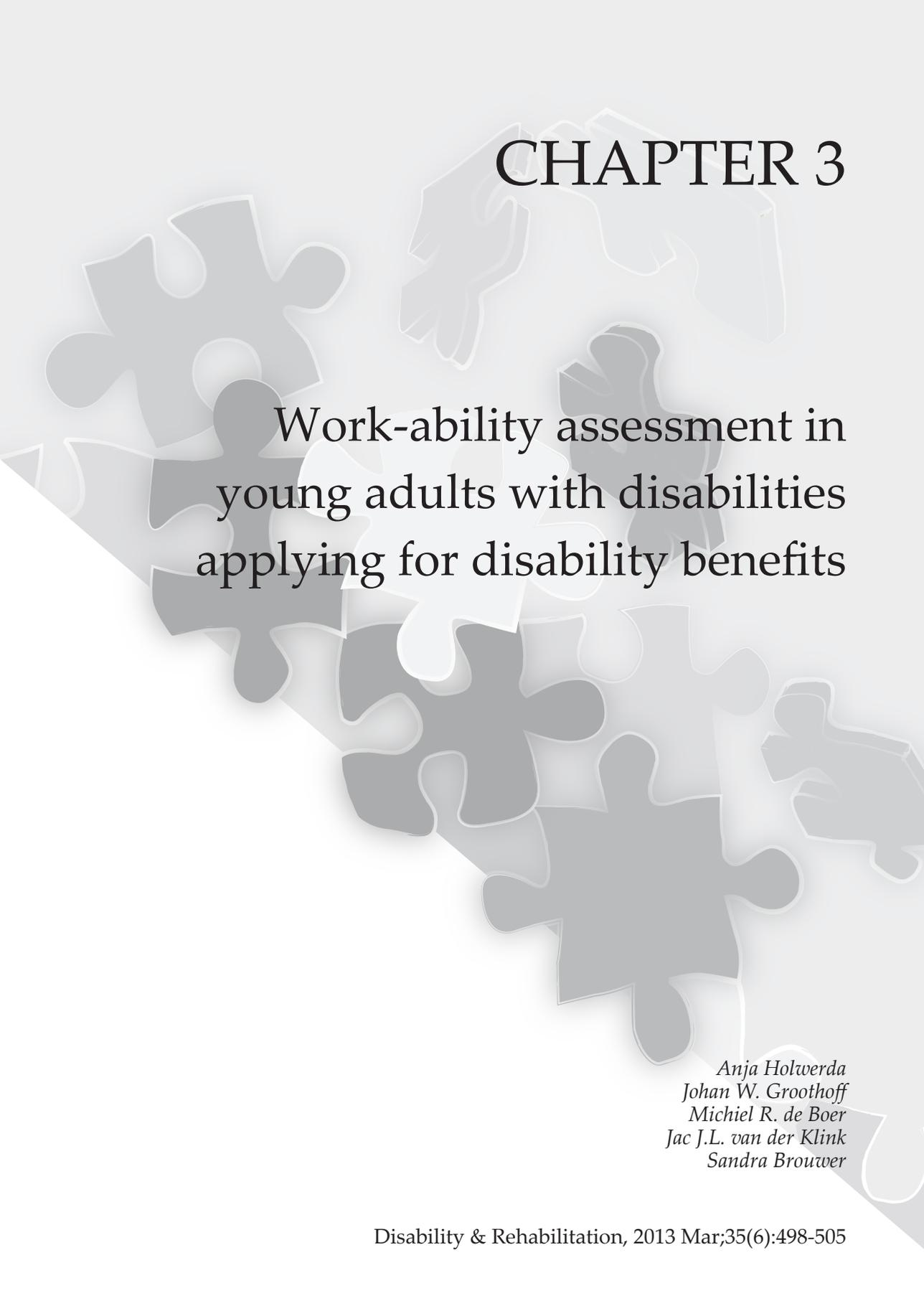
### **ACKNOWLEDGEMENTS**

This study was financially supported by a grant of the UWV Knowledge Centre of the Social Security Institute, The Netherlands. Further support has been received from the Social Security Institute in the three Northern provinces. We thank the staff of the SSI for assistance with questionnaire development and data collection. We thank the external scientific committee and the regional advisory committee for their contribution to the study.

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# CHAPTER 3

## Work-ability assessment in young adults with disabilities applying for disability benefits

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### **ABSTRACT**

**Purpose:** To investigate the impact of diagnosis, co-morbidity, secondary conditions (e.g. learning problems, subclinical mental and somatic complaints, addictions, and socio-emotional and behavioural problems) and problems in social context on work ability as assessed by Insurance Physicians (IPs) in young adults applying for a disability benefit.

**Method:** IPs of the Social Security Institute assessed young adults with disabilities (aged 15-27) applying for a disability benefit (n=1755). Data were analysed with multilevel ordinal regression techniques.

**Results:** Primary diagnosis, co-morbidity and subclinical mental complaints were associated with IP-assessed work ability. Persons with mental health conditions as primary diagnosis were less likely to reach a higher work ability than persons with somatic diseases. Young adults with two or more co-morbid conditions and those with psychiatric or developmental co-morbidity were less likely to reach a higher work ability level than persons without co-morbidity. Young adults with subclinical mental complaints were half as likely to reach a higher IP-assessed work ability than young adults without this condition.

**Conclusion:** Primary diagnosis, type and number of co-morbid conditions and subclinical mental complaints are associated with IP-assessed work ability. Work-ability assessments among adolescents with disabilities applying for disability benefits still focus mainly on medical factors.

#### *Abbreviations:*

*SSI = Social Security Institute*

*IP = Insurance physician*

*CAS = Dutch Classification for Occupational Health and Social Insurance*

## INTRODUCTION

Many young persons with disabilities need assistance and support to achieve a good quality of life and to be able to participate in social and economic life (e.g. work) on an equal basis with others (Ireys et al., 1996; Lindsay, 2011; Verdonschot et al., 2009). The lack of necessary support services can make people with disabilities overly dependent on family members or social protection (Misra et al., 2010; Takamine, 1998).

In the Netherlands, young people with disabilities diagnosed during childhood (before 18 years of age) can apply for a disability benefit at the Social Security Institute (SSI). Besides income support, the SSI provides access to support services to find work and if necessary support at the work place. In the Dutch system the insurance physician (IP) is responsible for assessing the work ability level during the disability claim assessment. In the literature work ability has been defined as the degree to which a person, given his health, is physically and mentally able to cope with the physical, mental, social, environmental and organisational demands at work (Fadyl et al., 2010; Tuomi et al., 1998). In the disability assessment practice the level of work ability is determined by estimating the claimants' chances to be able to find and retain work independently, earning at least minimum wage level, and by assessing their need for assistance and support. This concept of work ability is based on Tengland's basic definition of general work ability: "an ability to perform some kind of work (given some minimal training)" (Tengland, 2010) and defined on the WHO's International Classification of Functioning (ICF) level of "activities" and "participation" (WHO, 2001). Furthermore, a prognosis is made by the IP of the ability to work for the period until the age of 27. This is in line with the notion that young people with disabilities frequently experience delays in psycho-social development and need more time to reach their potential than their non-disabled peers (Boyle et al., 1994; Newacheck & Stoddard, 1994). Moreover, the need for assistance and support varies, depending on the underlying health condition, the stage of life, the level of individual functioning and environmental factors (WHO & World Bank, 2011). Between leaving school and the age of 27 they may further develop their social and practical skills which might affect their work ability.

The professional basis for the physician's judgement in assessing the claimants' ability to participate in work is unclear (Slebus et al., 2007). One model that is used as underlying framework is the WHO's ICF-model (WHO, 2001). The model stipulates that functioning, in our terms work-ability, encompasses mutually related components: disease and disorder, functions and structures, activities, participation, and personal and environmental factors. In recent systematic reviews on factors influencing work participation of young disabled people (Achterberg et al., 2009; Cunningham et al., 2000; Holwerda et al., 2012) several determinants from different components of

the ICF model were found to influence work outcome. As health related factors severity of condition, co-morbidity, chronic health conditions combined with mental retardation and inpatient treatment were found. Gender, age, educational level, IQ, psychosocial functioning were the personal factors found. Slebus et al. (2007) have also shown that age, gender and (perceived) health influence work ability.

Whether the IPs use a multi-factorial approach in line with the ICF-model in the work-ability evaluation among adolescents with disabilities applying for benefits is unknown. Their main focus seems to be on medical factors. Therefore, the aim of this study was to examine which factors were associated with IP-assessed work-ability level among adolescents with disabilities applying for disability benefits.

## **METHODS**

### **Sampling and procedure**

This cross-sectional study is part of a cohort study called 'Young Disabled at Work' investigating factors that predict work participation among young adults aged 15-27 year applying for a disability benefit at the Dutch Social Security Institute (SSI). This institute is responsible for all work-ability assessments under social security regulations. Participants eligible for the present study were recruited using registry data from the local SSI offices in the three northern regions in the Netherlands (Groningen, Friesland, Drenthe). Recruitment started at January 1st 2009 and ended at 31st December 2009. In the Dutch social security system, the disability benefit assessment for young persons with disabilities commonly takes place at the transition from school to work.

All twenty-one IPs employed by the SSI in the three regions participated in the study. During the claim assessment they were asked to fill out a registration form, which was developed prior to the start of the study in close collaboration between the researchers and the participating IPs. If the person was not seen by the IP, he or she was excluded, because no information about his or her disability was available. Written consent was provided by all subjects and approval was obtained from the ethics review board prior to the study. The Medical Ethics committee of the University Medical Center Groningen, the Netherlands, approved recruitment, consent and field procedures.

### **Measures**

Demographics (age and gender) were derived from SSI registers. Data regarding primary diagnosis, co-morbidity, secondary conditions and problems in social context were derived from the register forms filled in by the IPs. The level of work ability was the result of the complete assessment process within the SSI.

### **Primary diagnosis**

For primary diagnosis seven mutually exclusive diagnosis groups were differentiated, based on the IP's indication of the primary diagnosis code (CAS code) responsible for the claimant's disability. This classification system (CAS) has been derived from the ICD-10 and developed for use in occupational health and social security in the Netherlands (*Ouwehand & Wouters, 1997*).

The seven groups were: (1) severe to profound mental retardation, (2) moderate mental retardation, (3) mild intellectual disabilities, (4) autism spectrum disorders, (5) other developmental disorders, (6) other psychiatric disorders, and (7) somatic diseases.

### **Co-morbidity**

Based on the IP's indication of the secondary diagnosis code (CAS code) four groups were constructed to define type of co-morbidity: (1) intellectual disabilities, (2) psychiatric & developmental disorders, (3) somatic diseases, and (4) no co-morbidity. Besides this classification in type of co-morbidity, we also created three groups based on number of co-morbid conditions: (1) no co-morbidity, (2) one co-morbid condition and (3) two or more co-morbid conditions.

### **Secondary conditions**

Secondary conditions were assessed by the following yes/no question "Does the respondent have any secondary conditions, apart from the diagnoses, that influence the work ability of the respondent?" and "If so, what kind of problems are these?" with possible response options "Learning problems / Mental complaints (e.g. subclinical depression or anxiety) / Somatic complaints (e.g. headaches, eczema, etc.) / Problems with addiction (drugs, alcohol) / Socio-emotional & behavioural problems (including problems regarding motivation) / Other problems".

### **Problems in social context**

Problems in social context were assessed by a single item (yes/no) question: "Does the respondent have any problems in his/her social context?". It was explained to the IPs that these problems could consist of problems with addiction in the family (e.g. parental alcohol abuse), financial problems, problems with delinquency, domestic violence, and similar problems.

### **Work ability**

In accordance with the SSI assessment-outcome and with Dutch legislation on income compensation for young disabled, IP-assessed work ability was categorized as one of the four following categories: 1) able to work at minimum wage level independently (high work ability), 2) able to work but needing support to find and retain work (moderate work ability), 3) temporarily not able to work, e.g. due to hospitalization, but

re-assessment will take place after a specified period of time (low work ability).  
4) no ability to work due to the severity of the disability (no work ability).

### **Statistical Analyses**

We first compared participants with complete data with those with incomplete data on age and gender using a t-test and a chi-square test respectively. Multilevel ordinal logistic regression analyses were conducted in order to examine which factors were associated with work-ability, controlling for clustering of young disabled within IPs. These analyses yield one odds ratio for the comparison of consecutive categories of the outcome variable, i.e. the same odds ratio for the comparison of work ability category 2 vs 1, as for 3 vs 2 as for 4 vs 3. We entered the nine potential predictors (diagnosis, type and number of co-morbid conditions, secondary conditions (5 conditions) and social context) to the model simultaneously in order to determine their association with IP-assessed work ability while controlling for gender and age. Because the variables 'type of co-morbidity' and 'number of co-morbid conditions' both had 'no co-morbidity' as a reference category, we performed two separate analyses; one with each co-morbidity indicator. An alpha of 0.05 was used for all statistical tests. The non-response analyses were conducted in SPSS version 18 and the multilevel ordinal logistic analyses in STATA 11.2.

## **RESULTS**

### **Description of the sample**

Administrative data about gender and age was available for all disability claimants. The IP filled out a questionnaire for 99.9 percent of the included applicants (n=2274). The identity of the IPs assessing the work ability was known for 97.0 percent of the subjects (n=2206). Primary diagnosis was available for 98.3 percent of the subjects (n=2237). We excluded 95 individuals from the analysis, because they did not have any disability according to the IP (n=55) or because the severity of their mental retardation was unknown (n=40). The final sample for analysis consisted of 1755 complete cases (77.1%). Incomplete cases did not differ from complete cases with regard to gender and age.

The sample consisted of 1004 men (57.2%) and 751 women (42.8%) (see table 1), with a mean age of 19.6 years (SD 2.6). Of the subjects, 84.2 percent (n=1478) had abilities to work independently (high) or with support (moderate) according to the IP.

Of the total sample 42.5% had a primary diagnosis of intellectual disability, 28.2% had a developmental disorder, 16.9% had another psychiatric disorder, and 12.4% had somatic diseases. With regard to co-morbidity, 51.7% of the sample had one or more co-morbid condition(s). In addition, 21.9% of the sample had a secondary condition, of which learning problems and mental complaints were most common. Problems in social context were present for 19.0% of the respondents.

Table 1. Characteristics of young disabled applicants

	Total N (%)	No (4) N (%)	Work ability		
			Low (3) N (%)	Moderate (2) N (%)	High (1) N (%)
<b>Workability</b>	1755 (100%)	196 (11.2%)	81 (4.6%)	1210 (68.9%)	268 (15.3%)
<b>Gender (register data SSI)</b>					
- Male	1004 (57.2%)	103 (10.3%)	37 (3.7%)	721 (71.8%)	143 (14.2%)
- Female	751 (42.8%)	93 (12.4%)	44 (5.9%)	489 (65.1%)	125 (16.6%)
<b>Age (register data SSI)</b>					
- 15-20 year	1293 (73.7%)	151 (11.7%)	64 (4.9%)	953 (73.7%)	125 (9.7%)
- 21-27 year	462 (26.3%)	45 (9.7%)	17 (3.7%)	257 (55.6%)	143 (31.0%)
<b>Diagnosis (IP)</b>					
- Severe to profound mental retardation	35 (2.0%)	31 (88.6%)	0 (0.0%)	4 (11.4%)	0 (0.0%)
- Moderate mental retardation	77 (4.4%)	22 (28.6%)	3 (3.9%)	52 (67.5%)	0 (0.0%)
- Mild intellectual disability	634 (36.1%)	39 (6.2%)	20 (3.2%)	523 (82.5%)	52 (8.2%)
- Autism spectrum disorders	276 (15.7%)	8 (2.9%)	5 (1.8%)	222 (80.4%)	41 (14.9%)
- Other developmental disorders	219 (12.5%)	7 (3.2%)	7 (3.2%)	158 (72.1%)	47 (21.5%)
- Other psychiatric disorders	296 (16.9%)	66 (22.3%)	36 (12.2%)	131 (44.3%)	63 (21.3%)
- Somatic diseases	218 (12.4%)	23 (10.6%)	10 (4.6%)	120 (55.0%)	65 (29.8%)
<b>Co-morbidity (IP)</b>					
Co-morbidity present (yes)	908 (51.7%)	96 (10.6%)	41 (4.5%)	643 (70.8%)	128 (14.1%)
Type of co-morbidity					
- Intellectual disabilities	84 (4.8%)	5 (6.0%)	4 (4.8%)	66 (78.6%)	9 (10.7%)
- Psychiatric & Developmental Disorders	635 (36.2%)	63 (9.9%)	33 (5.2%)	461 (72.6%)	78 (12.3%)
- Somatic diseases	189 (10.8%)	28 (14.8%)	4 (2.1%)	116 (61.4%)	41 (21.7%)
- No co-morbidity	847 (48.3%)	100 (11.8%)	40 (4.7%)	567 (66.9%)	140 (16.5%)
Co-morbidity in number of conditions					
- Two or more co-morbid conditions	271 (15.4%)	39 (14.4%)	13 (4.8%)	186 (68.6%)	33 (12.2%)
- One co-morbid condition	637 (36.3%)	57 (8.9%)	28 (4.4%)	457 (71.7%)	95 (14.9%)
- No co-morbidity	847 (48.3%)	100 (11.8%)	40 (4.7%)	567 (66.9%)	140 (16.5%)
<b>Secondary conditions (IP)</b>					
Secondary conditions, like*	385 (21.9%)	31 (8.1%)	25 (6.5%)	277 (71.9%)	52 (13.5%)
- Learning problems	75 (19.5%)	6 (8.0%)	1 (1.3%)	57 (76.0%)	11 (14.7%)
- Mental complaints	79 (20.5%)	9 (11.4%)	6 (7.6%)	58 (73.4%)	6 (7.6%)
- Somatic complaints	58 (15.1%)	8 (13.8%)	3 (5.2%)	45 (77.6%)	2 (3.4%)
- Problems with addiction (drugs, alcohol)	65 (16.9%)	5 (7.7%)	10 (15.4%)	40 (61.5%)	10 (15.4%)
- Socio-emotional & behavioural problems	64 (16.6%)	2 (3.1%)	3 (4.7%)	48 (75.0%)	11 (17.2%)
- Other problems	44 (11.4%)	1 (2.3%)	2 (4.5%)	29 (65.9%)	12 (27.3%)
No secondary conditions	1370 (78.1%)	165 (12.0%)	56 (4.1%)	933 (68.1%)	216 (15.8%)
<b>Problems in social context (IP)</b>	333 (19.0%)	25 (7.5%)	13 (3.9%)	239 (71.8%)	56 (16.8%)

\* Categories are not exclusive

Table 2 provides an overview of the prevalence of co-morbidity, secondary conditions and problems in social context for each primary diagnosis group separately. Psychiatric and developmental disorders were found to be the most prevalent co-morbid condition (36.2%).

Secondary conditions were found most frequently in individuals with mental disabilities, like developmental disorders, mild intellectual disability and other psychiatric disorders. Problems in social context were assessed most frequently in individuals with psychiatric (28.0%) and other developmental disorders (27.4%).

### Association of diagnosis, co-morbidity and secondary conditions with work ability

The results of the multilevel analyses are presented in table 3. Because the separate analysis with both indicators of co-morbidity (type and number) yielded similar results for the other predictors in the model, we presented the model which included type of co-morbidity and added the results of the analysis with the number of co-morbid conditions to table 3. The results indicated that primary diagnosis, type and number of co-morbid conditions, presence of mental complaints and problems in social context were statistically significantly related to the IP-assessed work ability level. Persons with severe

Table 2: Prevalence of co-morbidity and secondary conditions per diagnosis group

Diagnosis →	Severe to profound mental retardation N (%)	Moderate mental retardation N (%)	Mild intellectual disabilities N (%)	Autism spectrum disorders N (%)	Other developmental disorders N (%)	Other psychiatric disorders N (%)	Somatic diseases N (%)	Total N (%)
<b>Total</b>	35	77	634	276	219	296	218	1755
<b>Co-morbidity</b>								
Intellectual disabilities	0 (0.0%)	0 (0.0%)	0 (0.0%)	41 (14.9%)	19 (8.7%)	7 (2.4%)	17 (7.8%)	84 (4.8)
Psychiatric & Developmental Disorders	8 (22.9%)	20 (26.0%)	234 (36.9%)	108 (39.1%)	116 (53.0%)	126 (42.6%)	23 (10.6%)	635 (36.2%)
Somatic diseases	10 (28.6%)	12 (15.6%)	64 (10.1%)	19 (6.9%)	20 (9.1%)	14 (4.7%)	50 (22.9%)	189 (10.8%)
No co-morbidity	17 (48.6%)	45 (58.4%)	336 (53.0%)	108 (39.1%)	64 (29.2%)	149 (50.3%)	128 (58.7%)	847 (48.3%)
<b>Secondary conditions</b>								
<b>Secondary conditions present</b>	5 (14.3%)	7 (9.1%)	150 (23.7%)	60 (21.7%)	66 (30.1%)	60 (20.3%)	37 (16.9%)	385 (21.9%)
Learning problems	0 (0.0%)	1 (1.3%)	32 (5.0%)	9 (3.3%)	15 (6.8%)	5 (1.7%)	13 (6.0%)	75 (4.3%)
Mental complaints	2 (5.7%)	3 (3.9%)	20 (3.2%)	25 (9.1%)	14 (6.4%)	9 (3.0%)	6 (2.8%)	79 (4.5%)
Somatic complaints	2 (5.7%)	2 (2.6%)	25 (3.9%)	8 (2.9%)	4 (1.8%)	7 (2.4%)	10 (4.6%)	58 (3.3%)
Problems with addiction	0 (0.0%)	0 (0.0%)	19 (3.0%)	9 (3.3%)	18 (8.2%)	19 (6.4%)	0 (0.0%)	65 (3.7%)
Socio-emotional & behavioural problems	1 (2.9%)	1 (1.3%)	32 (5.0%)	4 (1.4%)	10 (4.6%)	8 (2.7%)	8 (3.7%)	64 (3.6%)
Other problems	1 (2.9%)	1 (1.3%)	66 (10.4%)	16 (5.8%)	26 (11.9%)	24 (8.1%)	14 (6.4%)	148 (8.4%)
<b>Problems in social context</b>	0 (0.0%)	5 (6.5%)	129 (20.3%)	45 (16.3%)	60 (27.4%)	83 (28.0%)	11 (5.0%)	333 (19.0%)

mental retardation, moderate mental retardation, mild intellectual disability and other psychiatric conditions as the primary diagnosis were less likely to reach a higher work ability compared to persons with somatic diseases. The OR's (95% CI's) were 0.01 (0.00-0.02), 0.17 (0.10-0.30), 0.61 (0.42-0.88) and 0.25 (0.16-0.38) respectively.

Persons with two or more co-morbid conditions (OR 0.64, 95%CI: 0.46-0.88) and those with a co-morbid psychiatric or developmental disorder (OR 0.77, 95% CI: 0.60-0.97) had significantly lower odds to reach a higher level of work ability compared to persons without co-morbidity.

Persons with subclinical mental complaints were approximately half as likely to reach a higher IP-assessed work ability than respondents without this condition (OR 0.46, 95% CI: 0.28-0.75). Finally, problems in social context were statistically associated with work ability (OR 1.38, 95% CI: 1.05-1.83). The other secondary conditions were not statistically significantly related to IP-assessed level of work ability.

## DISCUSSION

The results of this study showed that insurance physicians seem to predominantly consider aspects related to the diagnosis in the work-ability assessment, i.e. primary diagnosis, type and number of co-morbid conditions and presence of mental complaints were statistically significantly related to the IP-assessed work ability level.

Young adults with intellectual disabilities or psychiatric disorders, young adults with two or more co-morbid conditions and young adults with subclinical mental complaints were less likely to reach a higher level of IP-assessed work ability.

In our study we found that both the number of co-morbid conditions as well as the type of co-morbid condition significantly influenced work ability.

**Table 3: Results multivariate multilevel analysis of prognostic factors and IP-assessed work ability**

Multivariate analysis (n=1755)	15-27 years of age					p
	Estimate	SE	OR	CI 95%		
				lower	upper	
Gender (male)	-0,042	0,112	0,96	0,77	1,19	0.704
<b>Age</b>						
[1] 15-20 years	-1,055	0,135	0,35	0,27	0,45	0.000
[2] 21-27 years (ref)						
<b>Diagnosis</b>						
[1] Severe to profound mental retardation	-4,836	0,570	0,01	0,00	0,02	0.000
[2] Moderate mental retardation	-1,769	0,290	0,17	0,10	0,30	0.000
[3] Mild intellectual disability	-0,501	0,189	0,61	0,42	0,88	0.008
[4] Autism spectrum disorders	-0,025	0,209	0,98	0,65	1,47	0.906
[5] Other developmental disorders	0,121	0,221	1,13	0,73	1,74	0.585
[6] Other psychiatric disorders	-1,384	0,215	0,25	0,16	0,38	0.000
[7] Somatic diseases (ref)						
<b>Type of co-morbidity</b>						
[1] Intellectual disabilities	-0,441	0,267	0,64	0,38	1,09	0.099
[2] Psychiatric & developmental disorders	-0,267	0,122	0,77	0,60	0,97	0.029
[3] Somatic diseases	0,154	0,183	1,17	0,81	1,67	0.401
[4] No co-morbidity (ref)						
<b>Number of co-morbid conditions *</b>						
[1] Two or more co-morbid conditions	-0,447	0,164	0,64	0,46	0,88	0.006
[2] One co-morbid condition	-0,092	0,119	0,91	0,72	1,15	0.440
[3] No co-morbidity (ref)						
<b>Secondary conditions</b>						
- Learning problems (yes)	0,238	0,263	1,27	0,76	2,12	0.366
- Mental complaints (yes)	-0,787	0,255	0,46	0,28	0,75	0.002
- Somatic complaints (yes)	-0,380	0,293	0,68	0,39	1,22	0.195
- Problems with addiction (drugs, alcohol) (yes)	-0,363	0,277	0,70	0,40	1,20	0.190
- Socio-emotional and behavioural problems (yes)	0,460	0,283	1,58	0,91	2,76	0.104
<b>Problems in social context (yes)</b>	<b>0,326</b>	<b>0,143</b>	<b>1,38</b>	<b>1,05</b>	<b>1,83</b>	<b>0.023</b>

\* We analysed one model with type of co-morbidity and another with number of co-morbid conditions. As the results for the other variables remained similar, we presented the model with type of co-morbidity and added the number of co-morbid conditions.

OR = odds to fall in a higher outcome category of assessed work ability compared to the reference category of the predictor

Other studies confirmed the negative impact of presence of co-morbidity on work outcome (Cook *et al.*, 2007; Dixon *et al.*, 1999; Waghorn *et al.*, 2006; Zieger *et al.*, 2011). Although in our study the presence of one co-morbid condition failed to reach significance, the trend is showing decreased odds on higher work ability.

The results of this study show that intellectual and psychiatric disabilities as primary diagnosis are associated with a lower level of IP-assessed work ability compared to somatic diseases. Also, the prevalence of co-morbidity, secondary conditions and problems in social context was higher in this group compared to somatic diseases. This is indicative of the vulnerability of this specific mental disorders group. The finding that the ability to participate in work of people with mental disorders is low, has been confirmed by other studies (Burstrom, 2010; Einfeld *et al.*, 2006). Randolph (2004) reported that only

32% of people with intellectual disabilities and 33% of people with mental health conditions are employed. In young adults with congenital heart disease, for example, this percentage was 64% (Kamphuis *et al.*, 2005) and in COPD 52% (Kremer *et al.*, 2006).

Secondary conditions were not often reported by the IPs, which could mean these were not taken into account in the assessment of work-ability and might also point to the lack of awareness of IPs of the influence of these conditions on work ability. Problems in social context were assessed in almost one in five cases. Although in our study it was significantly associated with the IP-assessed work ability level, the direction of the effect is counterintuitive. Literature suggests functioning of young adults with disabilities can be considerably hampered by problems in social context, such as domestic violence (Lindhorst *et al.*, 2007; Swanberg *et al.*, 2011). It seems unlikely that IPs would assess problems in social context as a facilitating factor for work ability. However, individuals with problems in social context may have developed a certain resilience and drive that causes the IP to think that these individuals are well able to find their way in entering the labour market. Our reverse finding might also be caused by the amount of missing data, resulting in selection bias, although other effects we found were in the expected direction. Another explanation could be that it was caused by a type I error, which might be plausible given the amount of factors tested in our model.

Any personal (secondary conditions) or environmental barriers individuals may have to enter the labour market may be considered irrelevant by the IP's, and therefore, unimportant. In a study of Slebus *et al.* similar results were found; both personal and environmental factors were not often mentioned by IPs as taken into account in the work-ability evaluation of long-term sick listed workers applying for a disability benefit (Slebus *et al.*, 2007). It can be argued that these factors should be incorporated in work-ability assessment more often, while it is known from literature that these factors influence work outcome among young people with disabilities. Several authors mentioned that learning problems are regularly occurring in individuals with developmental disabilities and mental retardation (Biederman *et al.*, 1991; Holwerda *et al.*, 2012; Kube *et al.*, 2002). Adolescents with mental disorders and developmental disabilities are attributed a higher risk of emotional and behavioural problems (Fussell *et al.*, 2005; Lecavalier, 2006; Pearson *et al.*, 2006) and substance abuse (Gilvarry, 2000; Lee *et al.*, 2011) compared with their healthy peers. Moreover, it was found that individuals with learning impairments, emotional and behavioural problems or substance abuse experience significant higher unemployment rates than the general population (Elbro *et al.*, 2011; McCoy *et al.*, 2007; Reijneveld *et al.*, 2003).

Because it is known that disease-related factors are weak indicators of work-ability (Slebus *et al.*, 2007) IPs should investigate personal and external factors as well, in line with the ICF-model, to ensure that those factors will not hinder work-ability. The low prevalences and weak relationships with work-ability of these non-disease related factors (secondary and environmental) found in our study suggest that IPs do not take into account these important factors in a structured way. An explanation might be the information sources the IPs rely on during their assessment. For the certification of diagnosis as reason for disability, insurance physicians mostly rely on the diagnosis of other professionals in the health care sector, i.e. general practitioners, medical specialists and occupational physicians. For additional information, such as secondary and environmental conditions, the IPs rely on information from the claimant. In the group of young people with disabilities, information from school and from parents is available as well. Self-report from persons with disabilities, especially with mental disorders, has sometimes been found to be inappropriate because of denial of illness or lack of insight on the part of the young adults (Salbach-Andrae *et al.*, 2009). Moreover, in a previous study by Oeseburg *et al.* (2010) it was shown that knowledge of teachers regarding prevalence of co-morbidity and secondary conditions in their pupils is also restricted.

### **Implications**

Limited recognition of co-morbidity and conditions unrelated to primary diagnosis (such as secondary conditions and problems in social context) may translate into suboptimal assessment of the work ability level by insurance physicians, and may subsequently limit access to support services to find work and if necessary support at the work place. As a result the chances of successful and sustainable work participation may be (severely) limited. Therefore, it is important for IPs to take these factors into account when assessing work-ability.

Although the work disability assessment itself will differ across different countries, we assume that the medical point of view, that dominated the disability assessment until recently, will also affect assessments in other countries. It is a challenge for medical doctors as well as other professionals to incorporate non disease related aspects into their assessment of their clients. Moreover, the results of our study are also applicable to vocational rehabilitation professionals, who support individuals in finding work. Not taking into account non disease-related factors may severely limit the possible work outcome.

### **Strengths and limitations of the study**

Our study is the first to assess the extent to which IPs take into account co-morbidity, secondary conditions and problems in social context of young adults applying for a disability benefit, in addition to primary diagnosis. The strengths of this study are the representativeness of the sample for the

population of young disability claimants in the Netherlands, the use of data reported by the IPs and the size of our cohort, allowing assessment of work ability per diagnosis group.

However, some limitations must be taken into account as well. First, a potential limitation is the amount of missing data resulting in analyses of 76.8% of the available cases. This may have led to a slightly different distribution of the primary diagnosis in our cohort. Compared with the data of the Social Security Institute, the prevalence of mild intellectual disability in our cohort is slightly higher than reported by the SSI (35.2% versus 29%) and the prevalence of other psychiatric disorders in our cohort is somewhat lower than reported by the SSI (17.3% versus 21%) (UWV, 2011). However, it is not expected that a slightly different distribution of diagnosis will have significantly altered our findings regarding the associations with workability. Secondly, the cross-sectional design of this study prohibits any inference of causality. There is an apparent need for longitudinal studies linking these prognostic factors to work outcome as well as determining the ability of IP-assessed work ability level to predict subsequent work participation adequately. Thirdly, the registration of non-disease related factors may have been limited by our operationalization of these factors in our study. IPs were asked to indicate other problems influencing the work ability of the respondent and problems in social context on the registration form and this might have led to an underreporting of non-disease related factors.

## **Conclusion**

Based on these results it is concluded that in work-ability assessments among adolescents with disabilities applying for disability benefits the main focus is still on medical factors (diagnoses, comorbidity and subclinical mental complaints). Although problems in social context were frequently reported and statistically significantly related to the IP-assessed work ability level, it is dubious whether IPs really take the impact of these problems on the work ability level into account given the counterintuitive direction of the effect.

In line with previous research that showed that non-disease related factors (secondary conditions and environmental factors) are strongly related to the level of work-ability, it can be argued that these non-disease related factors should be incorporated in work-ability assessment more often, while it is known from literature that these factors influence work outcome among young people with disabilities. Moreover, while the assessment of the work ability level is an important part of the evaluation for the work disability benefit and has considerable individual, financial and social consequences, it is suggested that IPs should be trained to take these factors into account in the work-ability evaluation of these claimants.

## **DECLARATION OF INTEREST**

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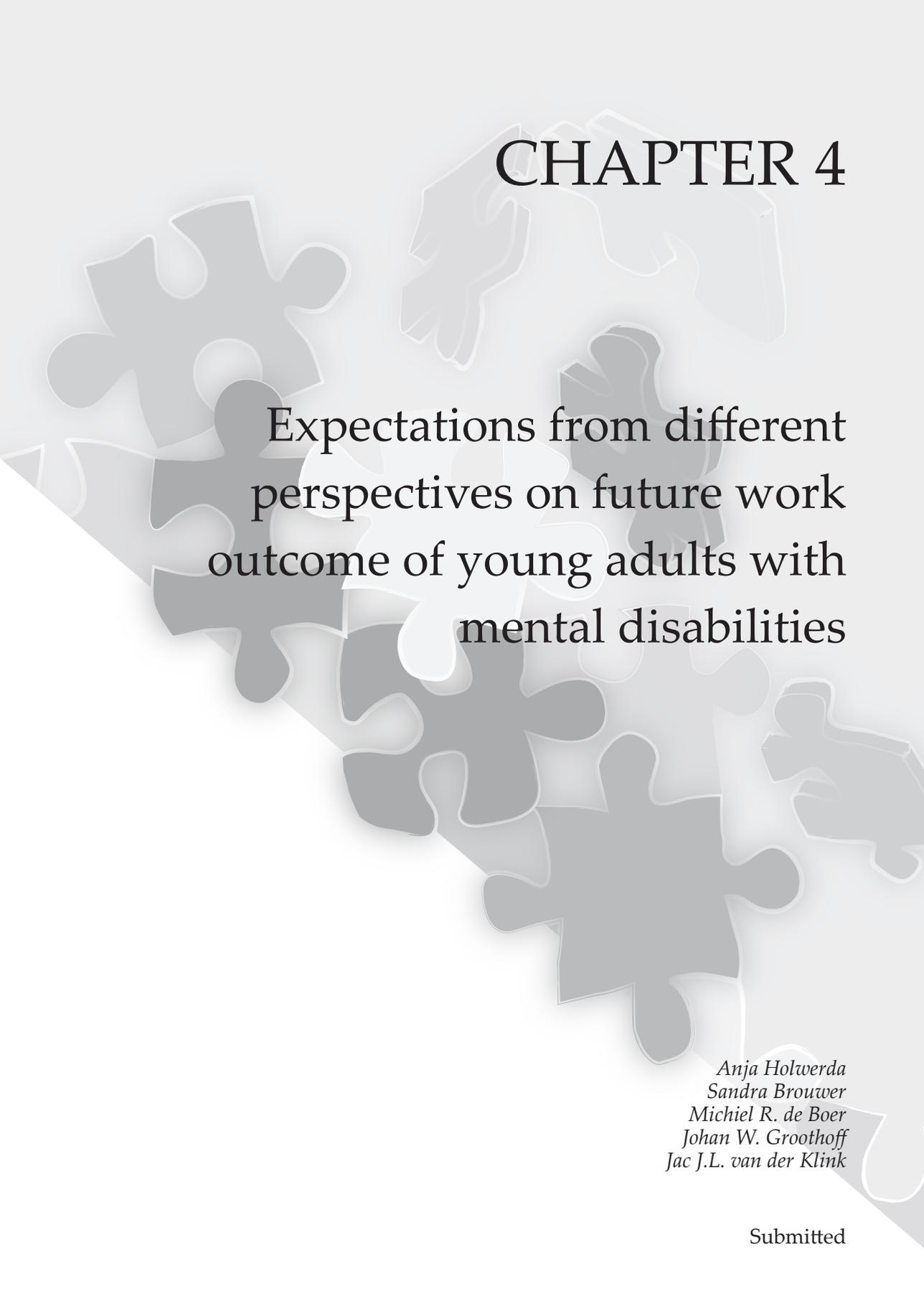
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# CHAPTER 4



Expectations from different  
perspectives on future work  
outcome of young adults with  
mental disabilities

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**ABSTRACT**

Expectations strongly influence future employment outcomes and several studies have noted the influential role of social networks in mediating the employment success of young adults with disabilities. Therefore, the aim of the current study is to examine the expectations of young adults with mental disabilities coming from special needs education, their parents and their school teachers regarding future work and the discriminative ability of these expectations to predict work outcome. Therefore, we examined data on 344 young adults with mental disabilities, aged 17-20 years and coming from special needs education. The expectation of the school teacher was the only perspective that significantly predicted entering competitive employment, with a complementary effect of the prediction of parents and a small additional effect of the expectation of the young adult. In conclusion, expectations of school teachers and parents are most valuable in predicting employment outcome.

**KEYWORDS**

Young adults with disabilities, expectations, mental disabilities, special needs education, transition to work.

## INTRODUCTION

Many young adults with disabilities lag behind in terms of education, employment, and independent living, compared to their peers in the general population (Geenen *et al.*, 2003). Although being employed is a valued adult role and a primary indicator of success in society (Eisenman, 2003; Lindstrom *et al.*, 2011; Wagner *et al.*, 2005), young adults with disabilities have a hard time finding and maintaining employment (Garcia-Iriarte *et al.*, 2007; Lindsay, 2011; Wagner & Blackorby, 1996). Compared to over 80% of young adults without disabilities (Lindsay, 2011) and almost 90% of students with a vocational training background (Statistics Netherlands, 2012), only about 50% of special education students with disabilities were competitively employed within two years after leaving school (Fabian, 2007; Test *et al.*, 2009; Wagner *et al.*, 2005). The participation rates of young adults with intellectual disabilities range from 10% to 40% (Ireys *et al.*, 1996; Lysaght *et al.*, 2012b; Rose *et al.*, 2005; WHO & World Bank, 2011) and similar rates apply to young adults with developmental disorders: 10% to 54% (Billstedt *et al.*, 2005; Engstrom *et al.*, 2003; Gjervan *et al.*, 2012; Halmoy *et al.*, 2009; Shattuck *et al.*, 2012; Wagner *et al.*, 2005). These mental disorders are the most common diagnoses among students in special needs education in the Netherlands. These special needs schools provide vocational training and internships for young adults with disabilities in the final years at school and appropriate job placements in the transition from school to work.

### Expectations about future work outcome

In the return to work and work disability literature, there is extensive evidence for a positive association between return to work expectations and return to work or work disability outcomes (Cornelius *et al.*, 2011; Dekkers-Sanchez *et al.*, 2008; Iles *et al.*, 2008; Laisne *et al.*, 2012; Tiedtke *et al.*, 2010). When individuals expect to return to work they are more likely to do so. This may also apply to young adults with disabilities in their transition from school to work, when entering competitive employment. The majority of transition-age young adults with disabilities, when asked about their future plans, indicated that they want to obtain a paid job (Betz & Redcay, 2005; Cameto *et al.*, 2004; Cooney, 2002; Wagner *et al.*, 2005; Wagner *et al.*, 2007). Wittenburg *et al.* (2002) suggested that the expectations of young adults with disabilities can have a major impact on transition decisions. For example, when students with disabilities had a transition goal of post-secondary education, they were more likely to enroll in college (Wittenburg *et al.*, 2002).

### Different perspectives on employment outcomes

Several studies have noted the influential role of social networks in mediating the employment success of young adults with disabilities (Carroll *et al.*, 2009; Carroll & Dockrell, 2012; Eisenman, 2003; Eisenman, 2007; Hughes, 2001; Test *et al.*, 2009). By role modeling and sharing information regarding their own occupations and their expectations for the young adult, family influences

the career interests and aspirations of the young adult (Eisenman, 2007). Especially parents' expectations for the future of their young adult with disabilities can be a powerful influence on the employment options, experiences and transition outcomes of their young adult after leaving school (Cooney, 2002; Doren et al., 2012; Eisenman, 2003; Lindstrom et al., 2007; Wagner et al., 2005). This influence can be positive as well as negative. The US National Longitudinal Transition study (NLTS-2) in students from special education reported that 90% of the parents expected their child to definitely get a paid job and 8% thought their child would probably get a paid job (Wagner et al., 2005). Another study found that young adults with disabilities were 2.7 times more likely to be working after secondary school, when their parents expected them to do so (Doren et al., 2012). According to the NLTS-2, family members played a supportive role in many aspects of the career development of young adults with disabilities (Eisenman, 2007). However, parents may also overestimate the abilities of their young adult and may have a hard time acknowledging that their expectations for their young adult are not realistic (King et al., 2005). On the other side, parents as well as teachers are said to underestimate the abilities of young adults with disabilities (EADSNE, 2006), which may hold back the young adult in reaching their full potential. Teachers substantially contribute to the educational achievements of students and the preparation of the young adult for the workforce and play a critical role in their subsequent transition to employment (Eisenman, 2007; Kim & Dymond, 2010; Laragy, 2004; Oeseburg et al., 2010; Wagner et al., 2007). The NLTS-2 found that school staff had a strong influence on the career development of young adults with disabilities (Eisenman, 2007). Another study found that teacher support predicted students' self-perceptions, which in turn predicted students' academic engagement and achievement (Fall & Roberts, 2012). Other studies found that perceived teacher support was related to greater academic achievement (Chen, 2005; Mercer et al., 2011). Academic achievement has been associated with positive employment outcomes (e.g. employment stability and higher income) in young adults in regular education (Carroll et al., 2009; Johnson et al., 2006; Sanders et al., 2001). Two NLTS-2 studies in young adults with disabilities showed a small similar effect (Eisenman, 2003; Sanford et al., 2011). Another NLTS-2 study did not find a significant difference in employment outcomes for high school completers and dropouts with disabilities (Wagner et al., 2005).

Currently there is little evidence regarding the value of expectations in predicting work outcome for young adults with mental disabilities. Furthermore, the contribution of the different perspectives to work outcome is unclear for this group of young adults that is generally more dependent on parents and school teachers than their peers without disabilities. The expectations of future work outcomes by young adults with special needs education, their parents and school teachers may be a valuable source of information predicting employment outcome.

Therefore, the aim of the present study is to examine the expectations of young adults with mental disabilities from special needs education, their parents and their school teachers regarding future work and the predictive value of these expectations on competitive employment.

## **METHODS**

### **Participants and procedure**

This study is part of a cohort study called 'Young Disabled at Work' in which factors that predict work participation among young adults aged 15-27 years applying for a disability benefit at the Dutch Social Security Institute (SSI) were examined. The SSI is responsible for all work-ability assessments under social security regulations. All participants applying for a disability benefit and eligible for the present study were recruited using registry data from the local SSI offices in the three northern regions in the Netherlands (Groningen, Friesland, Drenthe). For this study only participants with mental disabilities, attending special needs education, aged 17-20 years, and with an ability to work according to the SSI were included. The level of work ability is determined by estimating the claimants' chances to be able to find and retain work independently, earning at least minimum wage level, and by assessing their need for assistance and support to find and maintain work. For a detailed description of the work ability assessment in the Netherlands, see Holwerda et al. (Holwerda et al., 2012). Recruitment started at January 1st 2009 and ended at 31st December 2009. Written consent was provided by all claimants and the Medical Ethics committee of the University Medical Center Groningen, the Netherlands, approved recruitment, consent and field procedures prior to the study.

Preceding the disability assessment the participants were approached by the SSI to fill out a questionnaire consisting of questions that were partly adapted from an existing questionnaire of the 'Tracking Adolescents' Individual Lives' Survey' (TRAILS) questionnaire T4Youth based on the National Monitor Youth Health in the Netherlands (RIVM, 2005) and partly self-constructed. It was inappropriate to utilize existing questionnaires for this group, because of the limited cognitive abilities of the majority of the participants. School teachers of participants were also approached to fill out a questionnaire and in case participants resided with their parents, parents were also asked to fill out a questionnaire.

### **Measures**

#### *Work Outcome*

The cohort was linked to POLIS register data. The POLIS registry is a database, in which all Dutch workers are included that have earned any wage (from regular, supported or sheltered jobs) in the period concerned. This linkage was done quarterly, for a total of twelve different periods, from December 2008 until September 2011. Using these data, we constructed a

work outcome measure for 'entering competitive employment during 18 months of follow-up'. Only wage earning - for any number of hours - following disability assessment was taken into account. The follow-up period differed for the individuals in the study and started in the quarter following the disability assessment at the SSI. The maximum follow-up period was two years and nine months, the minimum follow-up period was 18 months.

#### *Expectations at baseline, with young adults still attending special education*

Expectation of young adult regarding future work was measured with one self-constructed question "Do you think you are able to work in competitive employment?" with response options yes, completely / yes, partly / no. From these responses a dichotomous variable was derived that contrasted ability (yes completely and yes partly) with no ability.

Expectation of parents regarding future work for young adult was based on the parent's response to the self-constructed question "In your opinion, what ability does your child have to participate in work?". Response options were regular work / supported employment / sheltered employment / day centre or voluntary work / no ability to work.

Expectation of school teacher regarding future work for young adult was based on the school teacher's response on the self-constructed question "In your opinion what ability does your student have to participate in work?". Response options were regular work / supported employment / sheltered employment / day centre or voluntary work / no ability to work.

The responses of parents and teachers were subsequently dichotomized into: (1) young adult is able to participate in competitive employment (regular work / supported employment), and (2) young adult is not able to participate in competitive employment (no ability to work / sheltered employment / day centre or voluntary work).

#### *Demographics*

Demographics (age and gender) of the young adults were derived from SSI registers. Data regarding diagnosis was derived from the register forms filled in by the Insurance Physicians of the SSI at baseline.

Education was based on the respondent's report at baseline on the question "Which education have you followed after primary school". Response options were Special Secondary Education / Practical Education / Secondary education / Vocational training / High school / Higher Education. The highest educational level mentioned was included.

Living situation was based on the respondent's report at baseline on two questions: (1) "What is your living situation?" with response options Parental home / Own place / Student home / Sheltered home / Institution or Hospital / Other and (2) "Who is living there with you?". Subsequently four mutually exclusive groups were constructed: (1) living independently with or without partner, (2) living with parents/family/foster family, (3) living in a supported/sheltered home, and (4) other living situations (RIVM, 2005).

## Statistical Analyses

Accuracy of the predictions of the participants, parents and school teachers were assessed by calculating the sensitivity, specificity and positive predictive value. 95% confidence intervals (CIs) based on normal distributions were calculated for each PPV estimate.

The accuracy of the prediction was also evaluated by calculating the Area Under the receiver operating characteristic Curve (AUC). The AUC is a measure of the diagnostic power of a test that summarizes the likelihood of a dichotomized outcome (entering competitive employment) at various cut-offs of a test, in this case an expectation. The area under this curve (AUC) represents the overall accuracy of a test, with a value approaching 1.0 indicating a higher sensitivity and specificity. The AUC usually ranges from 0.50 (no discrimination) to 1.0 (perfect discrimination) (Katz & Foxman, 1993). Next, the perspective (either young adult, parent or teacher) with the highest AUC was entered into a logistic regression analysis with actual work during follow-up as outcome and the perspective with the second highest AUC was added. From this model, the predicted probabilities were calculated, which were then used to calculate the AUC of this combined model. Subsequently also the last perspective was added to the logistic model and the AUC was calculated again. Finally, age and gender were also added to the logistic model as independent variables, to assess odds ratios and 95% confidence intervals for each of the perspectives adjusted for age and gender and to see which perspective was most predictive. All analyses were performed in PASW Statistics 18.0.3 (SPSS).

## RESULTS

### Description of the sample

Administrative data about gender and age was available for all participants (n=385). Of the participants (n=385), 41 (10.6%) were not included in the analysis, because they already worked at baseline and thus were not able to enter into competitive employment. Of the remaining participants (n=344), 86.3 percent filled in a questionnaire (n=297).

Of 82.0 percent of the participants also a parent-questionnaire was completed (n= 282). The school teacher filled in a questionnaire for 57.8 percent of the participants (n=199). There were data from all three perspectives for 163 (47.4%) of the participants. Participants with incomplete data did not statistically significantly differ from complete cases with regard to gender, age and diagnosis. The only significant difference was found in work outcome ( $p = 0.049$ ): participants with complete data found work more often than respondents with incomplete data.

The total sample consisted of 227 men (66.0%) and 117 women (34.0%), with a mean age of 17.8 years (SD 0.5). Of the participants, 38.7 per cent (n=133) entered competitive employment in the 18 months following claim assessment. Of them 43.2% worked fulltime, 36.8% worked part-time (12-32 hours a

**Table 1. Characteristics of young adults with mental disabilities from a special needs education background**

	Total N (%)	No work N (%)	Work at any time N (%)
<b>Work outcome</b>	344 (100%)	219 (63.7%)	125 (36.3%)
<b>Gender (data SSI)</b>			
- Male	227 (66.0%)	138 (63.0%)	89 (71.2%)
- Female	117 (34.0%)	81 (37.0%)	36 (28.8%)
<b>Age (data SSI)</b>			
- 17 years	81 (23.5%)	56 (25.6%)	25 (20.0%)
- 18 years	254 (73.8%)	156 (71.2%)	98 (78.4%)
- 19-20 years	9 (2.6%)	7 (3.2%)	2 (1.6%)
<b>Primary diagnosis (n=335)</b>			
- Intellectual disability	277 (82.7%)	174 (81.7%)	103 (84.4%)
- Psychiatric / Developmental Disorders	58 (17.3%)	39 (18.3%)	19 (15.6%)
<b>Education* (n=344)</b>			
- Special secondary education	144 (41.9%)	113 (51.6%)	31 (24.8%)
- Schools for practical training	200 (58.1%)	106 (48.4%)	94 (75.2%)
<b>Living arrangements * (n=342)</b>			
- Living independently (with or without partner)	5 (1.5%)	3 (1.4%)	2 (1.6%)
- Living with parents/family/foster family	298 (87.1%)	182 (83.5%)	116 (93.5%)
- Residential placement/sheltered accommodation	38 (11.1%)	32 (14.7%)	6 (4.8%)
- Other living situation	1 (0.3%)	1 (0.5%)	0 (0.0%)
<b>Expectation young adult with disability *</b>			
- Completely able to work in competitive employment	79 (23.0%)	31 (14.1%)	48 (38.4%)
- Partly able to work in competitive employment	113 (32.8%)	72 (32.9%)	41 (32.8%)
- Not able to work in competitive employment	105 (30.5%)	88 (40.2%)	17 (13.6%)
- Unknown	47 (13.7%)	28 (12.8%)	19 (15.2%)
<b>Expectation parent regarding ability to work</b>			
- Regular work	17 (4.9%)	10 (4.6%)	7 (5.6%)
- Supported employment	176 (51.2%)	90 (41.1%)	86 (68.8%)
- Sheltered employment	51 (14.8%)	44 (20.1%)	7 (5.6%)
- Day centre or voluntary work	34 (9.9%)	33 (15.1%)	1 (0.8%)
- No ability to work	4 (1.2%)	3 (1.4%)	1 (0.8%)
- Unknown	62 (18.0%)	39 (17.8%)	23 (18.4%)
<b>Expectation school teacher regarding ability to work</b>			
- Regular work	13 (3.8%)	3 (1.4%)	10 (8.0%)
- Supported employment	123 (35.8%)	59 (26.9%)	64 (51.2%)
- Sheltered employment	41 (11.9%)	31 (14.2%)	10 (8.0%)
- Day centre or voluntary work	22 (6.4%)	22 (10.0%)	0 (0.0%)
- No ability to work	0 (0.0%)	0 (0.0%)	0 (0.0%)
- Unknown	145 (42.2%)	104 (47.5%)	41 (32.8%)

<sup>a</sup> Self-report by young adult with special needs education

week) and 20.0% worked less than 12 hours a week. Most of the working respondents worked in retail (21.6%), for temporary job agencies (18.4%), in agriculture/food industry (13.6%) and health care (11.2%). The majority of respondents were granted a disability benefit (96.2%) and 3.8% were denied a benefit. Most respondents had an intellectual disability (82.7%). The majority of the participants came from schools for practical training (58.1%) and most lived with parents or family (87.1%). Of the young adults, 54.7% expected to be able to work in competitive employment. Of the parents 55.9% and of the school teachers 38.6% expected the young adult to be able to work competitively.

### Accuracy of prediction of entering competitive employment by young adults, parents and school teachers

The analyses regarding the accuracy of the predictions were performed on complete cases. The sensitivities of expectations (the percentage of young adults that are correctly identified as able to work in competitive employment) by the young adult with disability, their parents and school teachers varied between 0.87 and 0.92 and the specificities (the percentage of young adults that are correctly identified as unable to work in competitive employment) between 0.39 and 0.45 (see table 2). The positive predictive values varied between 0.51 and 0.54.

The area under the curve from the school teachers' perspective was the highest at 0.66 (95% CI: 0.58 - 0.74) (see table 2). When the perspective of the parent was added, the area under the curve increased to 0.69 (95% CI 0.61 – 0.78) and when the young adults' perspective was added to the model with parents and school teachers the area under the curve increased to 0.71 (95% CI 0.63 – 0.79).

The results of the logistic regression analyses are presented in table 3. The results indicate that the school teachers' expectation of ability to work in competitive employment was the only perspective statistically significantly related to entering competitive employment during 18 months of follow-up. When school teachers expected their student to be able to work in competitive employment, the respondents had a three times higher odds to enter competitive employment during follow-up compared to respondents with school teachers expecting that their student would not be able to work in

Table 2: Accuracy of prediction of entering competitive employment by young adult, their parent and school teacher

Prediction <sup>a</sup>	Entering competitive employment	Sensitivity	Specificity	AUC	95% CI	PPV	95% CI
n=163							
Young adult	61 (37.4%)	0.90	0.39	0.64	0.56 - 0.73	0.51	0.46 – 0.56
Parent	59 (37.6%)	0.92	0.39	0.65	0.57 - 0.74	0.51	0.46 - 0.56
School teacher	59 (37.1%)	0.87	0.45	0.66	0.58 - 0.74	0.54	0.49 – 0.59

<sup>a</sup> only complete cases were included in the analysis

competitive employment (OR 2.95, 95% CI: 1.10 – 7.95).

The same OR was observed for parents, but because of the slightly higher standard error, this relation did not reach statistical significance ( $p = 0.073$ ).

**Table 3: Logistic regression analysis of predictors of entering competitive employment during 18 months follow-up**

(n=153)	OR	95% CI		p
		lower	upper	
Age	.995	.445	2.224	.990
Gender	2.179	1.026	4.629	.043
Prediction by young adult	1.832	.638	5.266	.261
Prediction by parents	3.079	.900	10.535	.073
Prediction by school teachers	2.952	1.096	7.951	.032

## DISCUSSION

This study shows that young adults with mental disabilities from special needs education, their parents and their school teachers are moderately able to predict future work when asked about their expectations regarding the ability of the young adult to work in competitive employment. The expectation of the school teacher was the only perspective that significantly predicted entering competitive employment, with a complementary effect of the prediction of parents and a small additional effect of the expectation of the young adult.

Of the included students 36% did enter competitive employment. This rather low percentage of young adults from special needs education entering competitive employment has been found in other studies as well (*Fabian, 2007; Wagner et al., 2005*).

On the one side, this may be an effect of the legislation, the vocational programs that are available to this population, the availability of jobs and the readiness of the employers to integrate this population into the work force. On the other side, this may also reflect the limited abilities of these young adults. Teachers know the strengths and weaknesses of their students and can help their student to be realistic in their aspirations taking into account the student's limitations.

We did not find a significant effect of the expectations of parents on work outcome of the respondent. However, there was a complementary effect of the prediction of parents to the prediction of teachers. Parents were better able to predict that young adults would enter competitive work (sensitivity) and teachers were better able to predict that young adults would not enter competitive work (specificity). Literature suggests that parents can be a powerful influence on the employment options, experiences and outcomes of their young adults (*Cooney, 2002; Doren et al., 2012; Eisenman, 2003; Test et al., 2009; Wagner et al., 2005*). Our results suggest parents tend to overestimate the ability of their young adult. Parents may stimulate their child to achieve a sense of fulfilment by using their talents and abilities to the full (*Cooney, 2002*)

including finding suitable employment. On the other side parents may be able to assess the abilities of their child realistically, but their young adult did not enter employment because of external factors like the unavailability of jobs. The perspective of young adults was the least predictive. One reason for the somewhat lower discriminative value of the expectation of the young adult may be that the majority of our participants had an intellectual disability. It is hard for these young adults to adequately assess their own abilities. Our results, supported by other studies, show that co-operation between school teachers and parents appears to result in valuable information in the process to develop a realistic view of a young adult's skills (*Eisenman, 2003; EADSNE, 2006; Laragy, 2004*).

In the final years at school preparations should start for a smooth transition from school to work, including practical job training and job orientation (*Laragy, 2004*). As parents may have insight in the abilities as well as affinities of their young adult, their input is valuable for teachers in planning for the transition, e.g. which job placements would be suitable and which kind of support the young adult needs to be able to function well (*Eisenman, 2003*). A review of transition programs for young people with disabilities found that schools should support their teachers in involving both students and their parents in these decision-making processes to achieve the desired employment outcome (*Laragy, 2004*). If teachers and parents work together with the student to prepare for the labour market, they may also influence the expectations of the young adult to become more realistic and achievable.

### **Strengths and limitations of the study**

The strengths of this study are the longitudinal design and the use of register data for work outcome, measured quarterly, allowing accurate assessment of work outcome during the follow-up for the complete sample.

The limited availability of the expectations of teachers and missings in the expectations of young adults and parents, resulted in inclusion of only 47 per cent of the respondents in the analyses. Non-response analysis showed no statistically significant differences between the respondents with complete and incomplete data with regard to gender, age and diagnosis. However, more respondents with complete data found work during the follow-up than respondents with incomplete data. As we know many school teachers were reluctant to fill in a questionnaire for a respondent involved, when they did not think employment was a realistic option for this student, our results are mainly applicable to young adults from special needs education with the potential to be engaged in work according to the teacher. In addition, we cannot rule out the possibility that there might have been differences in the characteristics of parents and school teachers of responders and non-responders. The results might be biased because more concerned and involved parents and school teachers filled out a questionnaire. However, it is unknown whether the predictions of these parents and teachers are more

accurate than those from less concerned parents and teachers or not. The missing values will have caused less precise estimates of the parameters of interest.

As the young adults with mental disabilities included in this study were all applying for a disability benefit, they may not be representative for the population with mental disabilities in special needs education. However, the majority of young adults with mental disabilities in the Netherlands are educated in special needs education. Moreover, the majority of these young adults apply for a disability benefit, so no large differences between this population from special needs education and our sample are expected.

At baseline most of the respondents were still at school. It is unknown whether the young adults left school within the 18 months of follow-up. However, in the Dutch special needs educational system most young adults leave school at 18 years of age. As the majority of respondents was 18 years or older at baseline, we expect that most of them will have left school during the follow-up and were able to enter competitive employment.

### **Conclusion and recommendations**

Expectations of school teachers and parents seem to be most valuable in predicting future work outcome of young adults with mental disabilities from special needs education, even more so when these two perspectives are combined.

In the Dutch system the majority of students with mental disabilities are educated in special needs education classes. In the transition from school to work, they receive special assistance to develop vocational skills and to find a job, if the severity of their disability allows work. Co-operation of school teachers and parents in setting realistic expectations for the young adult is necessary to ensure the best possible employment outcomes for the young adult. Furthermore, It is important that the Social Security Institute incorporates the knowledge of school teachers and parents regarding the abilities of the young adult to enter competitive employment as a valuable source of information in the disability assessment when assessing work ability of the young adult.

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# CHAPTER 5

## Predictors for work participation in individuals with an autism spectrum disorder: a systematic review

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**ABSTRACT**

**Introduction:** Research shows that only about 25% of people with autism are employed.

**Method:** We conducted a systematic review on factors facilitating or hindering work participation of people with autism in longitudinal studies. An extensive search in biomedical and psychological databases yielded 204 articles and 18 satisfied all inclusion criteria. We assessed the methodological quality of included studies using an established criteria list.

**Results:** Seventeen factors were identified and categorized as disease-related factors, personal factors or external factors. Limited cognitive ability was the only significant predictor consistently found for work outcome. Functional independence and institutionalization were both reported by one study to be significantly related to work outcome. Inconsistent findings or non significant findings were reported for the other fourteen factors.

**Conclusion:** These findings emphasize the need for more high quality cohort studies focussing on work participation as the main outcome among people with autism.

**KEYWORDS**

Autism, work participation, predictors

## INTRODUCTION

Work participation is considered as an increasingly important health outcome (WHO, 2001). On the individual level it contributes to health and welfare (Waddell et al., 2007). On the societal level demographic pressure due to ageing and shrinking populations make a broad participation more and more imperative. At the same time participation in work by vulnerable groups is complicated by increasing demands in work. Young disabled people willing to enter the workforce experience barriers in acquiring and retaining work. Despite the relevance and although the impact of autism on social outcomes has been described in quite a few studies in the existing literature (Ballaban-Gil et al., 1996; Howlin, 2000; Howlin et al., 2004; Kobayashi et al., 1992; Larsen & Mouridsen, 1997), the body of knowledge regarding factors facilitating or hindering work participation of people with autism is limited.

### Autism

Autism, a life-long lasting developmental disability, affects social functioning, behavior, learning and cognition (Garcia-Villamizar et al., 2000; Hume et al., 2009). According to Kobayashi et al. (1992) three in four individuals with autism also have intellectual disabilities. Autism spectrum disorders (ASD) seem to be more prevalent in boys than girls (Kogan et al., 2009).

### Autism and work participation

Adults with autism have typically not been considered suitable candidates for employment in the work force (Garcia-Villamizar et al., 2000; Gerhardt & Lainer, 2011; Ridley & Hunter, 2006). Especially the social deficits typical for most people with autism hinder their integration in the work force (Ballaban-Gil et al., 1996; Jennes-Coussens et al., 2006). Research shows that only about 25% of people with autism are employed. These are mostly the more high-functioning individuals. Unemployment rates for individuals with ASD as well as mental retardation are especially high (Magill-Evans et al., 2008). They are mostly in sheltered employment, if employed at all (Parmenter & Knox, 1991).

Notwithstanding these limitations, there are several opportunities for work for these young disabled people, like regular work (including supported employment), sheltered employment, daytime activity or voluntary work (Garcia-Villamizar et al., 2000). People with autism can benefit from employment socially as well as personally (Ridley & Hunter, 2006). Employment can provide a daytime structure that is helpful for this group as well as social contacts that are otherwise difficult for them to maintain (Garcia-Villamizar et al., 2000; Garcia-Villamizar et al., 2002; Ridley & Hunter, 2006). Having a job also may facilitate their self-confidence, self-worth, independence and autonomy (Eggleton et al., 1999; Ridley & Hunter, 2006).

### **Factors associated with autism and work participation**

The available reviews describing autism and social outcome suggest that the majority of individuals with autism is unable to lead an independent life, including employment (Gillberg, 1991; Jennes-Coussens et al., 2006; Nordin & Gillberg, 1998; Rutter, 1970). Most individuals suffer (severe) persisting impairments in communication and social life limiting their independence and social functioning considerable, especially as demands on social adaptation and functioning increase with age (Gillberg, 1991; Howlin et al., 2004; Jennes-Coussens et al., 2006). Howlin (2000) suggests that, as far as high functioning individuals are concerned, employment levels may be more dependent on the area individuals live in and the available support services than on any other factors. Also access to supported employment programs for this group may increase chances to find and retain appropriate jobs (Howlin, 2000; Mawhood & Howlin, 1999). IQ, communicative speech at 5-6 years of age, the level of mental retardation, and other comorbidity are mentioned as important predictors for outcome in individuals with ASD (Gillberg, 1991; Gillberg, 1998; Nordin & Gillberg, 1998; Rutter, 1970). Of those with a comorbid intellectual disability (IQ scores < 50) few are capable of employment. Outcome for individuals with an IQ between 50 and 70 is more variable, but not much better. Outcome for individuals with an IQ of 70 or more seemed to be more promising but also more difficult to predict (Gillberg, 1991; Gillberg, 1998; Howlin, 2000; Nordin & Gillberg, 1998; Rutter, 1970). Besides deficits in cognitive and social functioning, limited independent performance and high dependence on caregiver support are considered important contributors to restricted outcome for individuals with ASD (Hume et al., 2009; Jennes-Coussens et al., 2006).

To our knowledge, the literature on factors associated with work participation in adulthood for people with ASD has not yet been reviewed systematically. In a recent review factors influencing the work participation of young disabled starters entering the labor market were identified (Achterberg et al., 2009). They found that male gender, higher education, high psychosocial level of functioning, low depression and high dispositional optimism were promoting factors in relation to employment. However, in their review no studies on autism were included.

The aim of this review is to systematically investigate the prognostic factors facilitating or hindering work participation of people with ASD.

### **METHODS**

We started conducting a systematic review of the scientific literature on prognostic factors related to work participation of people with ASD. However, we found only one study focussing on factors in relation to work outcome as a primary outcome measure; in most studies work outcome

measures were incorporated in an overall social outcome. Therefore, we decided to include also studies looking at overall social outcome, incorporating employment, which provided valuable information about work outcome as well. Studies on overall social outcome including employment, not reporting on work outcome specifically, were not included. The International Classification of Functioning was selected as an underlying framework because it takes the multidimensional nature of work participation into account and provides a broad view on predictors (WHO, 2001).

The first (AH) and second reviewer (SB) discussed search strategy, criteria for selecting studies, quality assessment and data extraction to reach consensus. In case of disagreement the third reviewer (JvdK) made the final decision.

### Literature search

An extensive search in biomedical and psychological databases was performed (PubMed, PsycINFO, Embase, Cinahl, ERIC, SocINDEX) to find relevant articles, using MeSH terms, subheadings and free text words. Original studies (in English, Dutch, German and French) were identified that were published till June 2011. Only longitudinal studies were included to be able to distinguish predictors of work outcome. The search strategy consisted of an autism component and a work-related outcome measure. In table 1 the search terms are presented.

**Table 1:** Search terms (\* = truncated)

Terms linked to	MeSH	Free text words
<b>Diagnosis</b>	Child Development Disorders, Pervasive * Asperger Syndrome Autistic Disorder	autism autistic disorder pervasive developmental disorder asperger syndrome
<b>Population</b>		Exclusion: Child and not adult
<b>Outcome measure</b>	Work Employment (exploded) Rehabilitation, Vocational (exploded) Vocational Guidance	career employment / employed / employee(s) occupation vocation job
<b>Study design</b>	Cohort studies Longitudinal Studies Prospective studies Follow-up Studies	cohort longitudinal prospective follow-up prognostic

To select relevant studies for this review, the following eligibility criteria were defined: 1) Studies reported on factors related to work participation or social outcome in people with autism, only if information about work participation or employment status were included; 2) autism had to be diagnosed during childhood by an expert (e.g. following DSM-IV or ICD-10 criteria). The inclusion criteria are:

- Types of studies: Cohort studies, follow-up studies or longitudinal studies with a minimum follow-up period of one year.
- Types of participants: Persons in the age bracket 18–64 years, with disability due to autism spectrum disorder, diagnosed before the age of 18.
- Types of outcome measures: Dependent variables: participation in work (regular, supported or sheltered) or social outcome with a work identifiable component.

Titles and abstracts were screened independently by two reviewers (AH, SB). Full papers were retrieved if the abstract provided insufficient data to enable selection. Moreover, other relevant articles were searched on the basis of the name of the first author of included articles and the reference lists. Reviews were excluded, but their reference lists were inspected for additional studies.

### **Data extraction**

Using a standardized form, the first reviewer (AH) extracted data on study design, source population, inclusion criteria, numbers of participants, length of follow-up, loss to follow-up, outcome, prognostic factors and statistical analysis. Meta-analysis of the study results was not possible due to the descriptive nature of the included studies, the different outcome measures used and the limited availability of data which could be used for pooling.

### **Assessment of methodological quality of included studies**

Two reviewers (AH, SB) independently assessed the methodological quality of all included articles in the final selection. The quality assessment of the selected studies was based on an established criteria list for assessing validity of prognostic studies, as recommended by Altman (*Altman, 2001*) and used in previous reviews (*Cornelius et al., 2011; Scholten-Peeters et al., 2003*). The internal validity was the main aspect judged to inform the reader about the quality of the studies regarding the aim of our review.

The criteria list consists of 16 items, each having yes/no/don't know answer options. We operationalized the criteria for this review and pilot tested this operationalization on four longitudinal studies excluded for this present review. The final criteria list is presented in Appendix 1 (*Nonkin Avochen et al., 2011*).

The quality of all included articles was scored independently by two reviewers (AH, SB). If sufficient information was available, the item was rated one point. When information was not given or the information given was unclear, the item was rated zero point. For the total quality score we added all points for

each study (maximum score 16 points).

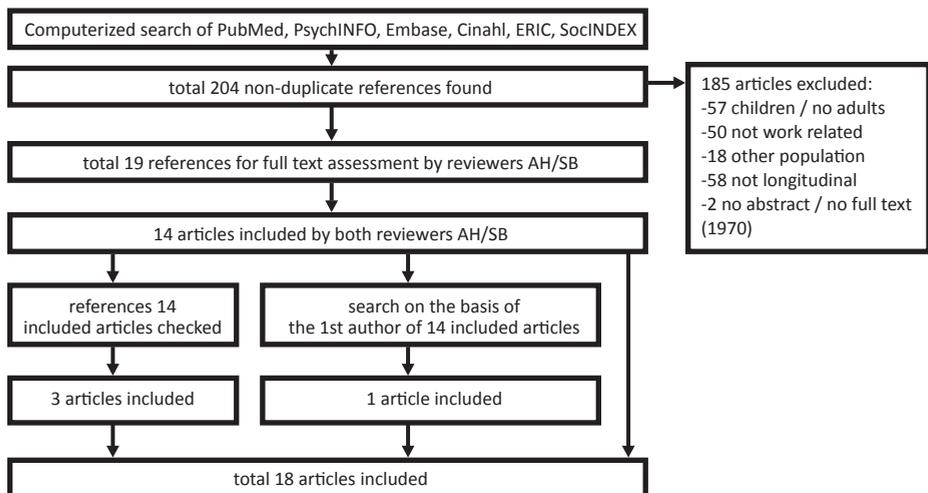
Studies with a minimum score of 11 points ( $\geq 70\%$ ) were arbitrarily considered to be of high quality and those with a score lower than 11 points ( $< 70\%$ ) of low quality. This cut-off score is in line with a previous review (Cornelius *et al.*, 2011). We calculated initial interobserver agreement on methodological quality using kappa statistics for dichotomous values.

## RESULTS

### Selection of studies

The initial search yielded 204 articles (search date: June 6th, 2011). After selecting 19 references for full text reading, both reviewers agreed to include 14 articles for the present review. Two articles were excluded because they were intervention studies. Three articles did not report on specific employment outcomes. Searching the reference lists of those included articles, we found and included 3 additional articles. Based on the name of the first author of the 17 included articles, we found 1 other relevant article. Table 2 shows a flow chart of study selection. In total we included 18 articles for the present review (Ballaban-Gil *et al.*, 1996; Billstedt *et al.*, 2011; Cederlund *et al.*, 2008; Eaves & Ho, 2008; Farley *et al.*, 2009; Fombonne *et al.*, 1989; Howlin *et al.*, 2000; Howlin *et al.*, 2004; Kobayashi *et al.*, 1992; Larsen & Mouridsen, 1997; Lotter, 1974; Ruble & Dalrymple, 1996; Rumsey *et al.*, 1985; Rutter *et al.*, 1967; Szatmari *et al.*, 1989; Taylor & Seltzer, 2011; Whitehouse *et al.*, 2009; Wolf & Goldberg, 1986) (Table 3).

**Table 2:** Flow diagram of study selection



### **Study characteristics**

The characteristics of each study regarding country, design, measurements, population, numbers enrolled, time to follow-up and loss to follow-up are presented in table 3. Time to follow-up varied considerably within as well as between studies, with the minimal time to follow-up being 3.2 years and 35 years at most.

### **Quality assessment and methodological considerations**

The final overall agreement between the two reviewers on quality score was  $\kappa=0.80$ , which is considered to be acceptable. Disagreement originated mainly from reading errors and misinterpretation of the criteria list and was readily resolved in a consensus meeting. The methodological quality of all included studies is summarized in Table 4. Four studies were considered of high methodological quality and fourteen of low quality. Statistical pooling of data in a meta-analysis was not possible because of the heterogeneity of study population and quality of the included studies.

### **Predictors for work participation**

Seventeen different prognostic factors were identified. In table 5 an overview of these factors related to work outcome is presented per included study. Table 6 gives an overview of these factors. The prognostic factors are categorized as disease/disorder related factors, personal factors or external factors based on the ICF-model (*Lagerveld et al., 2010; Ustun et al., 2003*). The only significant predictor for work outcome, consistently found in fifteen studies, is intelligence. Functional independence and institutionalization were reported in two separate low quality studies to be significantly predicting work outcome. Inconsistent findings were reported for diagnosis, severity of disorder, gender, language abilities, and maladaptive behavior. Non significant findings were reported for comorbidity, social impairments, lack of drive, parental support, family income, mental illness parents, family situation, treatment/use of medication and schooling.

### **Disease related factors**

#### **Diagnosis**

Six studies found that the more severe the disorder the lower the chance on a good outcome (*Cederlund et al., 2008; Eaves & Ho, 2008; Larsen & Mouridsen, 1997; Rutter et al., 1967; Taylor & Seltzer, 2011; Whitehouse et al., 2009*). With regard to work participation, one study reported that individuals who were competitively employed had significantly fewer autism symptoms than those who had a supported job or were participating in adult day activity programs (*Taylor & Seltzer, 2011*).

Table 3: Study characteristics

No	Study	Year	Country	Population (diagnosis, gender and age)	Numbers enrolled	Design	Baseline at	Time to follow-up	% Lost to follow-up
1	Rutter et al.	1967	United Kingdom	Individuals diagnosed as children with child psychosis, schizophrenic syndrome, infantile autism or any synonyms of these Gender: 51 male / 12 female Age: mean age 15.7 years (psychotic group) / 16.5 years (control group)	63 (infantile psychosis) 63 (control)	Follow-up study; 2 measurements; Medical or case records, assessments, structured interviews	Childhood assessment before the onset of any signs of pubescence	5-15 years	None (psychotics) 3% controls
2	Lotter	1974	England	Individuals showing appreciable evidence of autism syndrome. Autistic group(32) with most marked criterion behavior and comparison group (22) with similar but less marked features. Gender: not reported Age: 16-18 years	54 (32 autistic / 22 non-autistic)	Follow-up study; 2 measurements; Medical or case records, structured interviews	Childhood assessment at 8-10 years	8 years	7%
3	Rumsey et al.	1985	United States	Individuals with autism Gender: 14 males (100%) Age: 18-39 years	14	Follow-up study; Medical or case records, assessments, structured interviews	Unclear	-	-
4	Wolf & Goldberg	1986	Canada	Autistic individuals diagnosed between 1960 and 1973 Gender: not reported Age: 31% < 20 years 61% 20-30 years 7% >30 years	80	Follow-up study; 2 measurements Medical or case records, questionnaires	Childhood assessment between 1960-1973 at 1-15 years of age	8-24 years	20%
5	Szatmari et al.	1989	Canada	High-functioning individuals diagnosed with autism, childhood schizophrenia or childhood psychosis before age 5 and an last IQ score of above 65 Gender: 12 male / 4 female Age: 17-34 years	45	Follow-up study; 2 measurements Medical or case records, assessments, structured interviews	Childhood assessment of children born in 1970 and diagnosed before age 5	Variable 11-27 years	64%
6	Fombonne et al.	1989	France	Individuals diagnosed with childhood psychosis Gender: 77 male / 22 Female Age: 20-38 years (mean 27 years)	227 (Childhood psychosis n=55)	Follow-up study; 2 measurements; Questionnaires	Diagnosed during childhood	Range 6-25 years	56%
7	Kobayashi et al.	1992	Japan	Autistic individuals diagnosed as children. Gender: 170 male / 31 female Age: 18-33 years	201	Follow-up survey; 2 measurements Medical or case records, questionnaires	Diagnosed during early childhood or school age	Range 5-28 years	13%

No	Study	Year	Country	Population (diagnosis, gender and age)	Numbers enrolled	Design	Baseline at	Time to follow-up	% Lost to follow-up
8	Ruble & Dalrymple	1996	United States	Individuals diagnosed with autism meeting DSM-III-R criteria Gender: 33 male / 13 female Age: mean age 8.5 years (range 2-19) (T1) mean age 17.1 years (range 7-26) (T2)	46	Follow-up study (retrospective); 2 measurements Medical or case records, structured interviews	Diagnosed in childhood (mean age at diagnosis 5.2 years)	Mean follow-up time 8.6 years	-
9	Ballaaban-Gil et al.	1996	United States	Adolescents and young adults with autistic disorder Gender: not reported Age: 12 years or older (T2)	163	Follow-up study; 2 measurements Medical or case records, structured interviews	Childhood evaluation from May 1966 to May 1988: mean age 5 years and 2 months	Range 3.2 – 22.7 years	39%
10	Larsen & Mouridsen	1997	Denmark	Individuals considered to be either psychotic or borderline cases and diagnosed with Pervasive Developmental Disorder (childhood autism or Asperger syndrome) Gender: 10 male / 8 female Age: 32-44 years	18	Follow-up register study; 2 measurements Medical or case records	Childhood assessment between 1949-1970	30 years	11%
11	Howlin et al.	2000	United Kingdom	Individuals (all male) with autism or with developmental language disorders Gender: 47 male (100%) Age: 23-24 years on average	47	Follow-up study (comparative); 2 measurements; Assessments, structured interviews	Childhood assessment at 7-8 years	Around 15 years	17%
12	Howlin et al.	2004	England	Individuals diagnosed as having an autistic disorder. Gender: 61 males / 7 females Age: 21-49 years	79 (68 participants)	Follow-up study; 2 measurements Medical or case records, assessments, structured interviews	Childhood assessment prior to 16 years (range 3-15 years)	Variable (minimal 6 years)	14%
13	Cederlund et al.	2008	Sweden	Individuals with Asperger Syndrome and normal intelligence (IQ >70) and individuals diagnosed with autism or atypical autism before age 10 with different IQ levels Gender: 140 male (100%) Age: 16 – 38 years of age	140	Follow-up study (prospective); 2 measurements Medical or case records, assessments, structured interviews	AS group: Diagnosed between 1985-1999 at ages 5.5-24.4 years and born 1967-1988 Autism group: diagnosed before age 10	More than 5 years	30.0% in AS group 16.7% in autism group

No	Study	Year	Country	Population (diagnosis, gender and age)	Numbers enrolled	Design	Baseline at	Time to follow-up	% Lost to follow-up
14	Eaves & Ho	2008	Canada	Young adults born from 1974-1984 and diagnosed with ASD Gender: 37 males / 11 females Age: mean age 6.8 (range 3-12) (T1) mean age 11.4 (range 8-17) (T2) mean age 24 (T3)	48	Follow-up study; 3 measurements; structured interviews	Diagnosed as preschoolers	unknown	37%
15	Farley et al.	2009	United States	Individuals diagnosed with AD and an IQ $\geq$ 70 Gender: 38 males / 3 females Age: mean age 7.2 (range 3.1-25.9) (T1) mean age 32.5 (range 22.3-46.4) (T2)	75	Follow-up study; Assessments, structured interviews	Survey between 1984 and 1988 Childhood assessment except 1 participant	15-35 years	47%
16	Whitehouse et al.	2009	United Kingdom	Young adults with a childhood history of Specific Language Impairment or Pragmatic Language Impairment or with high functioning Autism Spectrum Disorder Gender: 35 male / 14 female Age: 16 – 31 years	49	Follow-up study; 2 measurements; structured interviews	Childhood assessment of children attending special speech and language schools	Not known	33%
17	Taylor & Seltzer	2010	United States	Youths with ASD who had exited the school system between 2004 and 2008 Gender: male 80% Age: 19 – 26 years	66	Follow-up study; 5 measurements; Structured interviews, questionnaires	Families of adolescents and adults with ASD of 10 years or older in 1998	10 years	Subsample of longitudinal study Not applicable
18	Billstedt et al.	2010	Sweden	Individuals with autistic disorder/ infantile autism or autistic-like conditions/ atypical autism diagnosed before 10 years of age Gender: 84 males / 36 females Age: mean age 25.5 years (range 17-40 years)	120	Follow-up study (prospective population-based); 2 measurements; Structured interviews	Childhood evaluation of children born in 1962-1984	Range 13-22 years	10%

Table 4: Results of methodological assessment<sup>a</sup>

No	Study	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Score	Quality
1	Rutter et al., 1967	0	1	0	1	1	0	1	0	1	1	1	1	1	1	0	0	10	Low
2	Lotter, 1974	1	1	0	1	1	0	1	0	0	0	0	1	1	1	0	0	8	Low
3	Rumsey et al., 1985	0	0	1	0	0	0	0	0	1	1	1	1	1	1	0	0	7	Low
4	Wolf & Goldberg, 1986	0	1	0	1	0	0	1	0	1	1	1	1	1	1	0	0	9	Low
5	Szatmari et al., 1989	0	1	1	1	0	1	1	0	1	1	1	1	1	1	0	0	11	High
6	Fombonne et al., 1989	0	1	0	1	0	1	1	0	1	1	1	1	1	1	0	0	10	Low
7	Kobayashi et al., 1992	0	1	0	1	1	0	1	0	1	1	1	1	1	1	0	0	10	Low
8	Ruble & Dairymple, 1996	0	0	0	1	0	0	1	0	1	1	1	1	1	1	0	0	8	Low
9	Ballaan-Gil et al., 1996	0	0	1	1	0	1	1	0	1	1	1	1	1	1	0	0	10	Low
10	Larsen & Mouridsen, 1997	0	1	0	1	1	1	1	0	1	1	1	1	1	1	0	0	11	High
11	Howlin et al., 2000	0	0	1	1	1	0	1	0	1	1	1	1	1	1	0	0	10	Low
12	Howlin et al., 2004	0	0	1	1	1	1	1	0	1	1	1	1	1	1	0	0	11	High
13	Cederlund et al., 2008	0	1	1	1	0	0	1	0	1	1	1	1	1	1	0	0	10	Low
14	Eaves & Ho, 2008	1	1	0	1	0	0	1	0	1	1	1	1	1	1	0	0	10	Low
15	Farley et al., 2009	0	1	1	1	0	0	1	0	1	1	1	1	1	1	0	0	10	Low
16	Whitehouse et al., 2009	0	0	0	1	0	1	1	0	0	0	0	1	1	1	0	0	6	Low
17	Taylor & Seltzer, 2010	0	1	1	1	0	0	1	0	1	1	1	1	1	1	0	0	10	Low
18	Billstedt et al., 2010	0	1	1	1	1	0	1	0	1	1	1	1	1	1	0	1	12	High
<b>Total</b>		<b>2</b>	<b>12</b>	<b>9</b>	<b>17</b>	<b>7</b>	<b>6</b>	<b>17</b>	<b>0</b>	<b>16</b>	<b>16</b>	<b>16</b>	<b>18</b>	<b>18</b>	<b>18</b>	<b>0</b>	<b>1</b>		

<sup>a</sup> See Appendix 1 for operationalization of items A-P

Table 5: Work outcome and related factors

No	Study	Factors (independent variables)	Type of work outcome	Outcome	Type of Work
1	Rutter et al., 1967	(1) Diagnosis of autism (D) (2) Severity of disorder (D) (3) Evidence of brain injury (D) (4) Intelligence (P) (5) Gender (P) (6) Useful speech at age 5 (P) (7) Response to sounds (P) (8) Underactivity/lack of drive/lack of initiative (P) (9) Schooling (E) (10) Family situation (E)	Employment (psychotics) Paid jobs n=2+1 Unpaid work n=1 Family business n=1 Day time activity n=3	(8) Underactivity, lack of drive and lack of initiative was often the chief factor preventing employment.	Paid work n=2 Unpaid typing and duplicating at home n=1 Helping in father's shop n=1 Various jobs n=3 Job following attendance Industrial Rehabilitation Unit n=1 Regular work n=1
2	Lotter, 1974	(1) Amount of Schooling (E) (2) Age excluded from school (E) (3) Age sent away from home (E)	Employment / placement history <i>Autistic group:</i> Employed n=1 Special school n=7 Training centre n=5 At home n=2 Long stay hospital n=14	-	Employed n=1
3	Rumsey et al., 1985	(1) Psychiatric disorders (D) (2) Stereotyped, repetitive and compulsive behavior (P) (3) Impairments in social behavior (speech & nonverbal communication) (P) (4) Parents (E)	Employment Competitive employment (routine jobs) n=4 Sheltered employment n=3 Job training n=3 Education n=1 Day program n=1 Unemployed n=2	(1) One patient's oppositional personality constituted an interfering factor for job success (2) One patient's compulsive habits, and rigidity constituted interfering factors for job success (3) One patient's obsessional questioning constituted an interfering factor for job success (3) One high functioning patient was fired because of his compulsive touching of other people and other inappropriate, intrusive social behavior (4) "parent factors" were influential in determining employment outcome. Parents played a major role in finding employers willing to give their sons a chance.	Janitor n=1 Cab driver n=1 Library aid n=1 Key punch operator n=1

No	Study	Factors (independent variables)	Type of work outcome	Outcome	Type of Work
4	Wolf & Goldberg, 1986	(1) Age of onset of symptoms (D) (2) Intelligence (P) (3) Gender (P) (4) Acquisition of speech for communication (P) (5) Living situation (home – institution) (E)	Employment Independent work n=5 Sheltered Workshop n=10 Education n=23 Day program n=21 No program n=5	(2) The autistic adults involved in competitive employment all had an IQ above 70.	Competitive employment n=4 Group employment outside institution n=1
5	Szatmari et al., 1989	(1) Aspects of cognition (P) (2) Impairments in social behavior (P) (3) Deviant language (P) (4) Bizarre behaviors (P)	Occupation or placement Paid employment n=6 Family business n=1 Sheltered work n=4 Education n=3 Unemployed n=2	-	Teacher-tutor n=1 Librarian n=1 Salesman n=2 Library technician n=1 Factory n=1 Family business n=1 Workshop n=4
6	Fombonne et al., 1989	(1) Age of admission (P) (2) Length of stay (E) (3) Gender (P) (4) Intelligence at time of admission (P) (5) Treatment (E) (a.o. psychotherapy, speech therapy, remedial gymnastics) (6) Medication (E)	Employment 55%	-	-
7	Kobayashi et al., 1992	(1) IQ at age 6 (P) (2) Level of speech development at age 6 (P)	Employment (21.8%) Paid jobs (mainly manual or industrial workers) n=41 Family business n=2 Education n=11 Sheltered workshop n=27 At home n=18	-	Laundry n=4 Bus conductor n=1 Chikwa maker n=1 Paper maker n=1 Food maker n=9 Tatami maker n=2 Civil servant / office worker n=3 Auto mechanic n=1 Helper n=2 Industrial worker n=9 Physical therapist n=1 Printer n=1 Trash collector n=2 Tile roofer n=1 Confectionary maker n=1 Construction/ Assitant plasterer n=2 Dressmaker n=1

No	Study	Factors (independent variables)	Type of work outcome	Outcome	Type of Work
8	Ruble & Dalrymple, 1996	(1) Cognitive level (IQ) (P) (2) Communication (P) (3) Challenging behavior (P)	Employment (adults) Supported employment n=1 Sheltered employment n=7 Daily living programs n=3 No program n=4 In institution n=2	-	-
9	Ballaban-Gil et al., 1996	(1) Intelligence (P) (2) Language (P) (3) Behavior (P) (4) Social deficits/impairment (P)	Employment adults (n=45) Open employment (menial jobs) n=5 Sheltered workshops n=6 Self employment n=2 Education n=7	-	Only 11% of adults were employed on the open market, all in menial jobs such as stock boy or mail clerk (n=5) Sheltered workshops n=6
10	Larsen & Mouridsen, 1997	(1) Diagnosis of autism (D) (2) Intensity of autistic symptoms (D) (3) Intelligence (P) (4) Psychiatric morbidity (D) (5) Pharmacotherapy (E)	Employment <i>Asperger group</i> : Paid job n=1 Sheltered employment n=2 Disability pension n=5 <i>Childhood autism group</i> : Paid job n=2 Sheltered employment n=1 Daytime program n=5	(1) In middle adulthood the Childhood Autism group has a much poorer outcome regarding education and employment than the Asperger group.	Insulator n=1 Porcelain painter n=1 Kindergarten teacher n=1 Received vocational training n=4 Before working as a driver/fish industry n=1 Fully-paid unskilled work before n=4
11	Howlin et al., 2000	(1) Diagnosis of autism (D) (2) Intelligence (P) (3) Psychiatric problems (D) (4) Early language abilities (P) (5) Autistic-like stereotyped and repetitive behavior patterns (P)	Education and employment histories <i>Autism group (n=19)</i> : Independent jobs n=1 Fulltime education n=2 Voluntary work n=3 Daytime centres n=12 No occupation n=1	-	Laboratory technician n=1

No	Study	Factors (independent variables)	Type of work outcome	Outcome	Type of Work
12	Howlin et al., 2004	(1) Childhood IQ (P) (2) Gender (P) (3) Speech at 5 years (P) (4) Autistic-type behaviors (P) (5) Social functioning (P)	Employment Independent jobs n=8 Self employed n=1 Sheltered employment n=11 Daily activities by centre n=15 Family based work activities n=2 Voluntary work n=1 No work activities n= 28 Not known n=2	(1) Individuals with a stable IQ from childhood to adulthood above 70 were more often in some form of employment (paid, voluntary or sheltered) (p = .005)	Scientific officer oil company n=1 Electrical work n=1 Cartographer n=1 Postal assistant n=1 Factory work n=5 Computing n=1 Accounts n=1 Fabric design n=1 Washing up n=1 Grave digger n=1 Office / accounts assistant n=1 Charcoal burning / gardening n=1 Administrative assistant n=1 Data input n=1 Supermarket trolleys n=1 Electronic work n=1 Special shop n=1 Decorating with father n=1 Office with parents n=1 Ordinary jobs n=8 Daily occupational activities n= 10
13	Cederlund et al., 2008	(1) Diagnosis of autism (D) (2) Intelligence (P) (3) Psychotic disorder (D)	Employment <i>Asperger group:</i> ordinary jobs n=7 "daily occupational activities" in a group centre n=6 no organized daily activity n=12 <i>Autism group:</i> ordinary job n=1 "daily occupational activities" in a group centre n=4 regular individually tailored daily activities n=33 no organized daily activity n=13	-	
14	Eaves & Ho, 2008	(1) Diagnosis (autism score) in adolescence (D) (2) Childhood and adolescence intensity of autistic symptoms (CARS) (D) (3) Childhood and adolescence verbal and Performance IQ (P)	Employment 56% (n=27) had ever been employed, most in volunteer, sheltered or part time work Independent job n=2 Daytime activity n= 19 (40%)		Delivering papers Meals on wheels Sorting recycle

No	Study	Factors (independent variables)	Type of work outcome	Outcome	Type of Work
15	Farley et al., 2009	(1) Psychiatric disorders (D) (2) Epilepsy (D) (3) Other medical disorders (D) (4) Historical full scale IQ (P) (5) Level of speech development at age 6 (P) (6) Adaptive behavior (P)	Employment Independent paid jobs n=22 Supported employment n=3 Voluntary work n= 2 Day programs n=10 Unemployed n=4	(1) In spite of high IQ scores and adequate practical skills, some participants were unable to seek employment due to difficulties with anxiety.	-
16	Whitehouse et al., 2009	(1) Diagnosis of autism (D) (2) Intensity of autistic symptoms (D) (3) Psychiatric problems (D) (3) Language ability (pragmatic or structural problems) (P) (4) Stereotyped and repetitive behaviors (P) (5) Social impairments (P)	Employment <i>Autism group (n=11):</i> Education n=5 Paid employment n=5 Never employed n=1	(1) Stable employment proved to be an area of difficulty for the ASD group.	Factory workers n=2 Cleaners n=3
17	Taylor & Seltzer, 2010	(1) Autistic symptoms (D) (2) Intellectual disability (P) (3) Comorbid psychiatric diagnoses (D) (4) Maladaptive behaviors (P) (5) Functional independence (P) (6) Family income (E)	Employment College/university n=9 Competitive employment n=4 Supported employment n=8 Adult day services n=37 No regular activities n=8	(1) Young adults who were competitively employed had fewer autism symptoms than those who had a supported job or were receiving adult day services (p<.01) (2) There was a significant relation between employment/day activity categories and ID status (p<.001) / Adults without ID were three times more likely to be competitively employed than those with ID, although percentages in supported employment were similar (4) Adults who were receiving adult day services had significantly more maladaptive behaviors than individuals who were in a post-secondary education program or competitively employed (p<.05)	Competitive: Bus boy Replacing dirty glasses with clean ones Salvation Army Bead business (self employed)  Supported: Rolling silverware into napkins in restaurant Folding towels in hotel Shredding confidential information Washing dishes at a nursing Working in a grocery store
18	Billstedt et al., 2010	(1) Intelligence (P)	Employment Regular job: n=1 Supported employment: n=7 Education: n=29 Day activity centres: n=52 No daytime occupation: n=19	(1) Correlations were found between IQ and occupational level (higher IQ correlating to having a daily occupation, p<.05)	Factory n=1

D = Disease/disorder related factor  
P = Personal factor  
E = External factor

## **Comorbidity**

Comorbidity (psychiatric disorder, oppositional personality or epilepsy) was mentioned by five studies as negatively influencing work outcome (Farley et al., 2009; Larsen & Mouridsen, 1997; Rumsey et al., 1985; Taylor & Seltzer, 2011; Whitehouse et al., 2009). No evidence was found that use of medication hinders a favorable work outcome (Fombonne et al., 1989).

## **Personal factors**

### **Gender**

In two studies gender was mentioned as a predictor for outcome, in that females might be more likely to have a poor outcome than males (Howlin et al., 2004; Wolf & Goldberg, 1986). In a third study (Fombonne et al., 1989) female gender was not found to be a hindering factor for positive outcome.

### **Intelligence**

Higher IQ facilitates a positive work outcome (Ballaban-Gil et al., 1996; Billstedt et al., 2011; Cederlund et al., 2008; Eaves & Ho, 2008; Farley et al., 2009; Fombonne et al., 1989; Howlin, 2000; Howlin et al., 2004; Kobayashi et al., 1992; Larsen & Mouridsen, 1997; Ruble & Dalrymple, 1996; Rutter et al., 1967; Szatmari et al., 1989; Taylor & Seltzer, 2011; Wolf & Goldberg, 1986); see also (Gillberg et al., 1991) and (Gillberg, 1998). One study reported that all individuals involved in competitive employment had an IQ above 70 (Wolf & Goldberg, 1986) and another reported that individuals with a stable IQ above 70 were more often in some form of employment (Howlin et al., 2004). Individuals without intellectual disability were three times more likely to be competitively employed than individuals with an intellectual disability (Taylor & Seltzer, 2011). Higher IQ was significantly correlated to having a daily occupation (Billstedt et al., 2011). According to Howlin (Howlin, 2000; Howlin et al., 2004) individuals of higher IQ in general had a better outcome and problems were less pervasive (see also (Ballaban-Gil et al., 1996; Rumsey et al., 1985; Rutter et al., 1967). IQ < 50 is often associated with poor outcome (Rutter et al., 1967). Fombonne et al. (1989) found a significant worse outcome for the group with an IQ of 80 or below. In the study of Larsen & Mouridsen (1997) normal intelligence predicted good outcome.

Table 6: Overview of factors associated with outcome

Prognostic factors (independent variables)	Study	Significance	Quality of study
<b>Disease/disorder related</b>			
<i>(Autism) diagnosis</i>			
– (Autism) diagnosis	Rutter et al., 1967	n.s.	Low
	Larsen & Mouridsen, 1997	-	High
	Howlin et al., 2000	-	Low
	Cederlund et al., 2008	Sig	Low
	Whitehouse et al., 2009	-	Low
– Autism score in adolescence	Eaves & Ho, 2008	Sig	Low
– Age of onset of symptoms	Wolf & Goldberg, 1986	n.s.	Low
– Evidence of brain injury	Rutter et al., 1967	n.s.	Low
<b>Severity of disorder</b>			
– Severity of disorder	Rutter et al., 1967	Sig.	Low
	Wolf & Goldberg, 1986	n.s.	Low
	Larsen & Mouridsen, 1997	-	High
	Eaves & Ho, 2008	Sig	Low
	Whitehouse et al., 2009	-	Low
– Intensity of autistic symptoms	Taylor & Seltzer, 2010	Sig	Low
<b>Comorbidity</b>			
– Psychiatric disorders	Rumsey et al., 1985	-	Low
	Larsen & Mouridsen, 1997	-	High
	Howlin et al., 2000	-	Low
	Cederlund et al., 2008	Descriptive	Low
	Farley et al., 2009	-	Low
	Whitehouse et al., 2009	Descriptive	Low
	Taylor & Seltzer, 2010	n.s.	Low
– Epilepsy	Rutter et al., 1967	n.s.	Low
– Other medical disorders	Farley et al., 2009	-	Low
	Farley et al., 2009	-	Low
<b>Personal factors</b>			
<i>Intelligence (IQ-level)</i>			
– Intelligence (IQ-level)	Wolf & Goldberg, 1986	-	Low
	Ruble & Dalrymple, 1996	Sig	Low
	Ballaban-Gil et al., 1996	Descriptive	Low
	Larsen & Mouridsen, 1997	Predictor	High
	Billstedt et al., 2010	Sig	High
– Full scale IQ	Szatmari et al., 1989	-	High
	Cederlund et al., 2008	-	Low
– IQ at diagnosis	Rutter et al., 1967	Sig	Low
– Intelligence at time of admission	Fombonne et al., 1989	Sig	Low
– IQ at age 6	Kobayashi et al., 1992	Sig	Low
– Performance IQ at Time 1	Howlin et al., 2000	-	Low
– Childhood IQ	Howlin et al., 2004	Sig	High
– Childhood and adolescence verbal and performance IQ	Eaves & Ho, 2008	Sig	Low
– Historical full scale IQ	Farley et al., 2009	Sig	Low
– Intellectual disability	Taylor & Seltzer, 2010	Sig	Low
<b>Gender</b>			
	Rutter et al., 1967	n.s.	Low
	Wolf & Goldberg, 1986	Sig	Low
	Howlin et al., 2004	-	High

Prognostic factors (independent variables)	Study	Significance	Quality of study
<i>Language / speech</i>			
– Communication	Ruble & Dalrymple, 1996	Descriptive	Low
– Language	Ballaban-Gil et al., 1996	Descriptive	Low
– Speech and language	Rumsey et al., 1985	-	Low
	Wolf & Goldberg, 1986	-	Low
– Language ability (pragmatic or structural problems)	Whitehouse et al., 2009	-	Low
– Acquisition of speech for communication	Wolf & Goldberg, 1986	-	Low
– Early language abilities	Howlin et al., 2000	Descriptive	Low
– Level of speech development at age 6	Kobayashi et al., 1992	Sig (males)	Low
	Farley et al., 2009	-	Low
– (Useful) speech at age 5	Rutter et al., 1967	Sig	Low
	Howlin et al., 2004	Sig	High
– Deviant language	Szatmari et al., 1989	n.s.	High
– Response to sounds	Rutter et al., 1967	-	Low
<i>Maladaptive behavior</i>			
– Ritualistic and compulsive behavior	Rutter et al., 1967	Descriptive	Low
– Stereotyped, repetitive & compulsive behavior	Rumsey et al., 1985	-	Low
– Bizarre behaviors	Szatmari et al., 1989	n.s.	High
– Challenging behaviors	Ruble & Dalrymple, 1996	Descriptive	Low
– Behavioral difficulties	Ballaban-Gil et al., 1996	Descriptive	Low
– Autistic-like stereotyped and repetitive behavior patterns	Howlin et al., 2000	-	Low
	Whitehouse et al., 2009	-	Low
– Autistic-type behaviors	Howlin et al., 2004	-	High
– Maladaptive behaviors	Taylor & Seltzer, 2010	Sig	Low
– Adaptive behavior	Farley et al., 2009	-	Low
<i>Social deficits/impairment</i>			
– Social deficits/impairment	Rumsey et al., 1985	-	Low
	Ballaban-Gil et al., 1996	Descriptive	Low
	Whitehouse et al., 2009	-	Low
– Impairments in social behavior (speech & nonverbal communication)	Rumsey et al., 1985	-	Low
	Szatmari et al., 1989	n.s.	High
– Social functioning	Howlin et al., 2004	-	High
Underactivity/lack of drive/lack of initiative	Rutter et al., 1967	-	Low
Functional independence (ADL)	Taylor & Seltzer, 2010	Sig	Low
<i>External factors</i>			
Parents	Rumsey et al., 1985	-	Low
Family income	Taylor & Seltzer, 2010	n.s.	Low
History mental illness parent	Rutter et al., 1967	n.s.	Low
Family situation (not living at home)	Rutter et al., 1967	n.s.	Low
Age sent away from home	Lotter, 1974	-	Low
Institutionalization	Wolf & Goldberg, 1986	Descriptive	Low
Treatment	Rutter et al., 1967	n.s.	Low
Use of medication / Pharmacotherapy	Fombonne et al., 1989	n.s.	Low
	Larsen & Mouridsen, 1997	-	High
Schooling	Rutter et al., 1967	-	Low
Amount of schooling	Lotter, 1974	-	Low
Age excluded from school	Lotter, 1974	n.s.	Low

n.s. = not significant

Sig = significant

### **Language / speech**

Language abilities and level of useful speech may influence outcome in that better linguistic abilities might support better outcome (*Ballaban-Gil et al., 1996; Farley et al., 2009; Howlin, 2000; Howlin et al., 2004; Kobayashi et al., 1992; Rutter et al., 1967; Whitehouse et al., 2009; Wolf & Goldberg, 1986*). However, speech may be highly correlated with IQ (*Howlin et al., 2004; Szatmari et al., 1989*). Howlin (2000) compared an autism group with a developmental receptive language disorder group and found that early language abilities appeared to be closely related to later adult functioning in the autism group. Kobayashi et al. (1992) reported that the positive effect of early speech development only occurs in males and not in females; Rutter et al. (1967) found that the level of speech at 5 or 6 years of age was closely related to IQ and low IQ contributes significantly to poor outcome.

### **Maladaptive behavior**

The presence of odd, challenging or ritualistic behavior, including self-injury, aggression and uncooperative behaviors, interferes with daily functioning (*Ballaban-Gil et al., 1996; Farley et al., 2009; Howlin, 2000; Howlin et al., 2004; Kobayashi et al., 1992; Ruble & Dalrymple, 1996; Rumsey et al., 1985; Rutter et al., 1967; Szatmari et al., 1989; Taylor & Seltzer, 2011; Whitehouse et al., 2009*). Individuals in post-secondary education or competitively employed had significantly lower levels of maladaptive behaviors than individuals receiving day services (*Taylor & Seltzer, 2011*). Szatmari et al. (1989) found a high correlation between adaptive behavior and IQ. According to some authors behavioral difficulties can be a critical limiting factor for functioning successfully in employment (*Ballaban-Gil et al., 1996; Rumsey et al., 1985*).

### **Social impairments**

The presence of social impairments, the lack of social skills and empathy are associated with poor outcome (*Ballaban-Gil et al., 1996; Howlin et al., 2004; Lotter, 1974; Rumsey et al., 1985; Szatmari et al., 1989; Whitehouse et al., 2009*). It is suggested that social impairments are likely to affect the ability of individuals with autism to find and remain in meaningful employment (*Beadle-Brown et al., 2005*).

### **Education**

The relationship between education and employment for individuals with autism seems to be ambiguous. The majority of people with autism have attended special education services and many left school without any formal qualifications (*Cederlund et al., 2008; Eaves & Ho, 2008; Fombonne et al., 1989; Howlin, 2000; Howlin et al., 2004; Rumsey et al., 1985; Rutter et al., 1967; Whitehouse et al., 2009*). However, people with high functioning autism have more often completed post-secondary education than other individuals with ASD (*Cederlund et al., 2008*). In Lotter's study (1974) all individuals with good and fair outcome had had at least 7 years of education. In spite of the educational attainment of high-functioning individuals, few of them were competitively employed and if employed often in routine jobs (*Lotter, 1974; Rumsey et al., 1985*).

### **Lack of drive**

Underactivity, lack of drive and lack of initiative often hinder people with ASD to find competitive employment (*Rutter et al., 1967*); see also (*Lotter, 1974; Rumsey et al., 1985*). Lotter (1974) mentioned three necessary requirements for being able to participate in regular employment: practical competence (e.g. literacy, practical skills), social competence (being able to relate to people in a meaningful way) and intentional competence (e.g. taking initiative, motivation).

### **External Factors**

#### **Family**

Parents play a major role in the outcome of their children with ASD. Many individuals with ASD continue to live with their family well into adulthood. According to Wolf and Goldberg (1986) 87 percent of the individuals residing at home were involved in schools, workshops or independent work, compared to 46 percent in institutions.

Seven articles mentioned parents searching for job opportunities and finding jobs for their children or providing a job in a family business rather than finding a job through the open job market (*Howlin, 2000; Howlin et al., 2004; Kobayashi et al., 1992; Lotter, 1974; Rumsey et al., 1985; Rutter et al., 1967; Szatmari et al., 1989*). Howlin et al. (2004) commented that for individuals to be able to function adequately as adults the degree of support offered by families, social services and work environment may be as important as intellectual ability.

#### **Institutionalization**

Institutionalization (i.e. hospitalization) hinders a positive outcome of individuals with ASD. Especially the lower functioning individuals are living in residential care, like special institutions and hospitals where staff can attend to their specific needs. Also quite a few individuals with ASD were part of day time programs in a specialized setting (*Cederlund et al., 2008; Howlin, 2000; Howlin et al., 2004; Larsen & Mouridsen, 1997; Rumsey et al., 1985; Rutter et al., 1967; Wolf & Goldberg, 1986*). These settings might not be the stimulating environment people need to be able to grow in their competences and work skills, although this applies to individuals with ASD as well as without (*Garcia-Villamizar et al., 2000; Garcia-Villamizar et al., 2002*).

#### **Work outcome**

The selected studies used different, but comparable, outcome measures regarding work participation and overall social outcome (incorporating education/employment, independent living and social relationships). Jobs were generally low level, unskilled and low pay jobs (*Ballaban-Gil et al., 1996; Eaves & Ho, 2008; Howlin et al., 2004; Rumsey et al., 1985*). Some individuals, however, managed to find a higher level job. Most individuals received special assistance in finding employment.

Few reasons are given for individuals previously employed but no longer

participating in work. Rumsey (1985) mentioned one individual was fired because of inappropriate social behavior. Kobayashi (1992) mentioned conflicts with fellow employees, financial crisis, motivation, hospitalization and other personal circumstances (death of a parent) as causes for quitting a job. Larsen & Mouridsen (1997) mentioned loss of supportive parents, divorce and factories closing down as hindering factors for finding permanent employment.

### **CONCLUSION AND DISCUSSION**

This study identified seventeen factors related to work outcome of people with ASD. Most of these factors are of importance for all individuals with or without autism. However, it may not be just one single factor, but the combination that leads to limited employment outcomes. Especially in individuals with ASD were a combination of these factors occurs frequently. Some of these factors may be interdependent, making interpretation of the results more complex. For example, some studies found high correlations between IQ and language abilities and IQ and adaptive behaviour in individuals with ASD. The disorder related characteristics (intensity of autistic symptoms, psychiatric comorbidity and epilepsy) and personal characteristics (limited language abilities, behavioral problems, social impairments) typical for ASD are factors which may, separately or combined, hinder individuals with ASD to participate in work in a sustainable way. Rates of employment among individuals with ASD are generally low. Often the impairments and social deficits of these individuals are emphasized leading to low expectations regarding outcome. However, these individuals may have strengths (e.g. ability to concentrate; strong focus) that can be utilized if the right tasks and settings are provided (Gillberg, 1998). In some of the studies Asperger syndrome and childhood autism were separately analyzed. There is a continuing discussion whether it is possible and necessary to distinguish between childhood autism and Asperger syndrome (Gillberg, 1998; Howlin, 2003; Volkmar et al., 2009). A pronounced autistic disorder often leads to substantial limitations in participation in work; people with Asperger syndrome often achieved higher education and have more abilities to work compared to childhood autism. However, this advantage in education does not always lead to higher levels of employment in later life (Howlin, 2003).

IQ is the only childhood predictor of work outcome for which we found consistent evidence in the literature in that a higher IQ facilitates a positive work outcome. Although an IQ below 50 does almost always lead to a poor outcome (Howlin et al., 2004) and this applies to individuals without ASD as well (Dusseljee et al., 2011; Verdonschot et al., 2009), individuals with an IQ of 70 or higher do not necessarily have a good outcome. Outcome in individuals without intellectual disability is much more variable and less predictable. Therefore, it seems that the clinical value of IQ in predicting individual outcomes is limited.

Although education is often mentioned as an important factor for outcome, job level is rarely consistent with educational background. Also the increase in educational services for children with ASD has not necessarily led to improved outcome when they have grown up (Howlin *et al.*, 2004). As access to education can be closely associated with the IQ of the individual, this relationship must be regarded with caution (Rutter, 1970). Nevertheless there is some evidence that the amount of schooling received, positively influences social adjustment in later life (Dusseljee *et al.*, 2011; Rutter, 1970).

Besides disorder-related and personal factors, several external factors are related to work outcome. Considering the low levels of independence of individuals with ASD, the degree of support offered by families, the available support services and the willingness of employers to incorporate this group in their work force may be as decisive for individuals to be able to function adequately in employment as the personal factors mentioned above (Howlin *et al.*, 2004; Vila *et al.*, 2007). Especially parents play an important role in supporting their children as they continue to live with them well into adulthood, in searching for job opportunities and in being advocates for their child's well-being (Howlin, 2000; Howlin *et al.*, 2004).

Competitive paid employment is often regarded as successful participation. Because of increasing demands in work, employers are hesitant to hire individuals with disabilities. If working, many individuals with ASD work in unskilled, routine, industrial jobs with limited decision latitude and minimal social interaction (Howlin *et al.*, 2000; Jennes-Coussens *et al.*, 2006; Rumsey *et al.*, 1985). As our economy becomes more knowledge-based, and globalization transforms and eliminates unskilled jobs, those with limited cognitive function may become increasingly marginalized (Kirsh *et al.*, 2009). Also periods of employment are alternated by periods of unemployment or temporary jobs (Howlin *et al.*, 2004). Data of the Dutch Social Security Institute suggest that about 11% (n=1618 per year) of the young disabled applying for a social security benefit has ASD (UWV, 2009).

If employed, the majority is working part-time, sometimes less than 10 hours a week (Eaves & Ho, 2008). Fulltime work is not always feasible for this group. For successful sustainable work participation a fit between the individual, the job and the work environment is essential (Kirsh *et al.*, 2009). This person-environment fit - or Person-Job fit when focussed on work (Edwards, 1991) - concerns the balance between knowledge, skills, abilities, attitude and motivation of the person at the one hand and work and its context at the other hand. A situation of balance contributes to the health, well-being and work-functioning of the employee. A disbalance leads to stress and disfunctioning. We can distinguish two kinds of PE-fit: the demands-abilities fit and the needs-supply fit (Edwards, 2007). In people with autism both their abilities and their needs can be influenced by the disorder. From a theoretical point of view tailor-made adjustment in demands and supplies (support) may be necessary to ensure a good fit. The practice of part time work might be a reflexion of this.

Considering the severe consequences of autism and the consequential need for special attention for a tailor-made fit between individual and work characteristics, it is important that effective assessments and interventions with respect to work participation of the ASD population are available. Over the last years, special vocational re-integration services and supported employment services have been set up for individuals with ASD, because existing services are not always accessible to them as services sometimes require a basic set of skills of applicants, like interpersonal communication skills, to increase employability (Lawver et al., 2009; Ridley & Hunter, 2006). Part of the supported employment strategy is to adapt the environment and workplace to the needs of disabled individuals who have the skills to do a certain job (Schneider, 2008). According to Garcia-Villamizar et al. (2000; 2002) supported employment produces favorable results for people with ASD as compared to sheltered employment services with regard to severity of impairments and quality of life. Ridley and Hunter (2006) reviewed the practice of supported employment in Scotland and found that the principles of supported employment are not widely and consistently applied, while adherence to these principles is related to improved employment outcomes (McGrew & Griss, 2005). Moreover, people with ASD have limited access to these services and unpaid and part-time jobs were more frequently achieved than paid jobs. Leadership by local authorities is needed to improve implementation of supported employment and accessibility. This supports Howlin's (2000) claim that the area where an individual lives and the available services is a major influence in outcome with regard to employment.

Autism spectrum disorders are studied extensively since the 70's and more attention is given to social functioning. Unfortunately, only one study focussed on employment as primary outcome. Most of the studies we reviewed were descriptive in nature and thus the quality of the data is variable and often limited. Few studies were able to report significant findings. Moreover, numbers of participants in the studies were often limited. Also quite a few studies in our review consisted of clinical samples, that by the nature of their population have limited generalizing capacity, because of problems with representativeness of these samples. Due to the diverse reporting of outcome it is not possible to compare the studies or to statistically pool the data. For that same reason we did not use the quality assessment for determining levels of evidence for the factors, but to inform the reader about the quality of the studies included. If the results of high quality studies differ from the results of low quality studies, this can be an indication of bias. In our review we found conflicting results for maladaptive behavior between one high and one low quality study (Szatmari et al., 1989; Taylor & Seltzer, 2011). Two early studies (Lotter, 1974; Rutter et al., 1967) were conducted in a very different climate with regard to the employment of individuals with disability. Their results seem to indicate that work outcomes did not improve in recent years.

## Recommendations

This review gives an overview of factors facilitating or hindering work participation of people with autism. Factors, identified in high quality studies, can help to provide an evidence-based ground for the development of instruments and intervention programs to increase work participation of individuals with ASD. The availability of adequate services for these individuals during their education, their transition from school to work and to independent living might influence employment outcome considerably (see also *Gerhardt & Lainer, 2011; Howlin, 2000; Rutter et al., 1967*). The findings of this review emphasize the need for adequate intervention and services, geared to the needs of the individual with ASD, that help them to adjust to the psychosocial demands in society (*Whitehouse et al., 2009*).

However, this review also painfully points to an important gap in the literature regarding predictors of work outcomes in individuals with ASD. High quality studies on predictors of work participation in individuals with ASD are lacking. Most of the included studies reported on outcome as an overall social outcome measure, including work; not on work as a primary outcome measure. In our study we assumed the seventeen factors we found are useful in predicting work outcome. However, further research should focus on work participation as the primary outcome measure in determining whether the factors mentioned are indeed influencing work outcome in individuals with ASD. High quality longitudinal studies are needed to identify variables that are responsive to interventions and that take the person-environment fit into account. Only then there is enough base for developing and implementing evidence based strategies to enhance optimal work participation for this group, that could benefit considerably from it in terms of quality of life.

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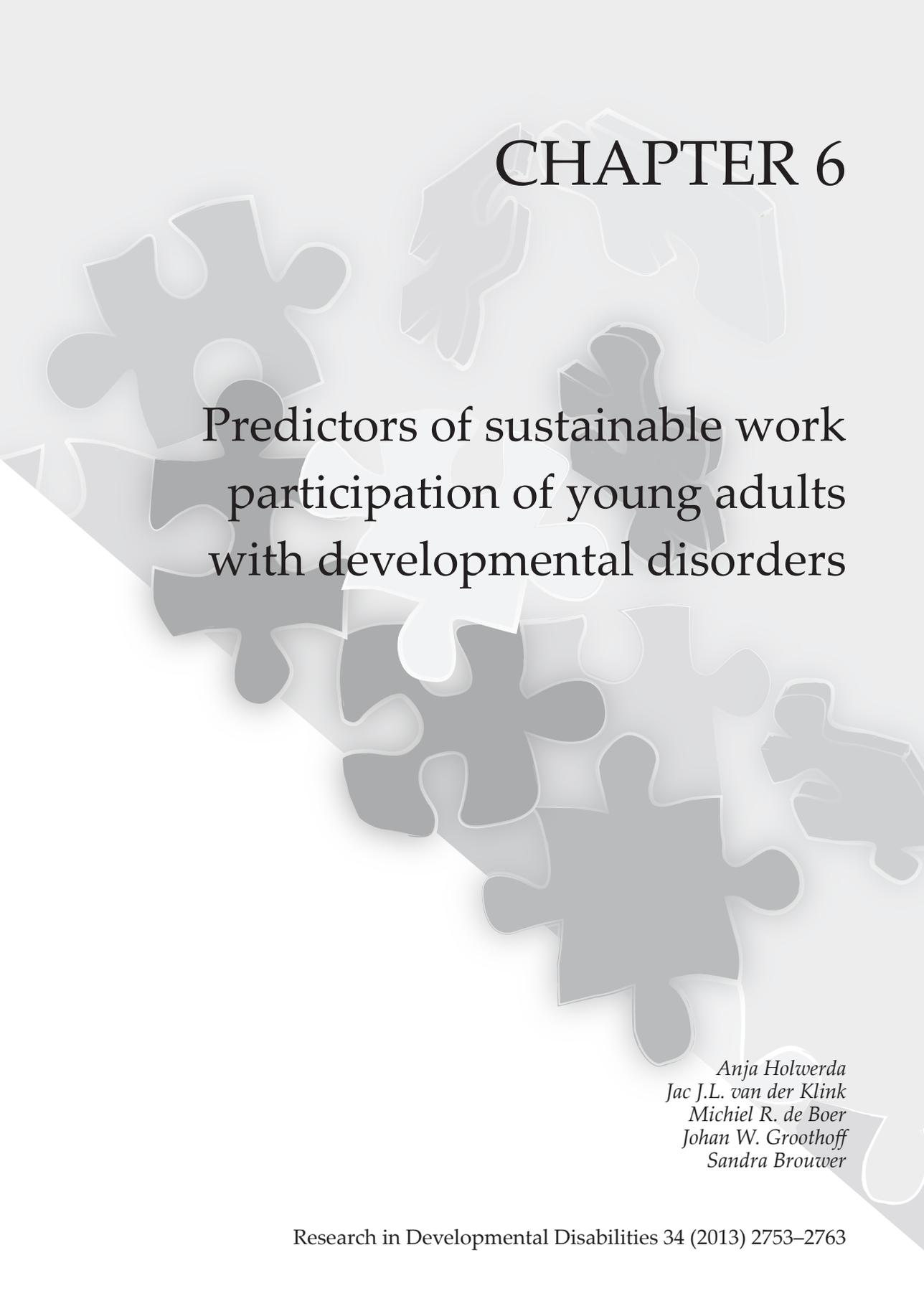
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## Appendix 1: Operationalization of criteria list for quality assessment

Study population	A Inception cohort
	<ul style="list-style-type: none"> <li>One point if participants are identified at an early uniform point in the course of their disability</li> <li>Zero point if it is not clear if an inception cohort was used.</li> </ul>
	B Description of source population
Follow-up	<ul style="list-style-type: none"> <li>One point if the source population is described in terms of place of recruitment (for example: Groningen, the Netherlands), time-period of recruitment and sampling frame of source population (for example: health service provider, special education services).</li> <li>Zero point if <math>\leq 2</math> features of source population are given.</li> </ul>
	C Description of relevant inclusion and exclusion criteria
	<ul style="list-style-type: none"> <li>One point if <math>&gt; 2</math> criteria are formulated.</li> <li>Zero point if <math>\leq 2</math> criteria are formulated.</li> </ul>
	D Follow-up at least 12 months
	<ul style="list-style-type: none"> <li>One point if the follow-up period is at least 12 month and data are provided for this moment in time.</li> </ul>
	E Drop-outs/loss to follow-up $< 20\%$
	<ul style="list-style-type: none"> <li>One point if total number of drop-outs/loss to follow up <math>&lt; 20\%</math></li> </ul>
Treatment	F Information completers versus loss to follow-up/drop-outs
	<ul style="list-style-type: none"> <li>One point if sociodemographic information is presented for completers and those lost to follow-up/drop outs at baseline, or no loss to follow-up/drop outs. Reasons for loss to follow-up/drop outs have to be unrelated to the outcome. Loss to follow-up/drop outs: all participants of the assembled cohort minus the number of participants at the main moment of measurement for the main outcome measure, divided by the total number of participants of the assembled cohort.</li> </ul>
	G Prospective data collection
Prognostic factors	<ul style="list-style-type: none"> <li>One point if a prospective design is used, or a historical cohort when the prognostic factors are measured before the outcome is determined.</li> <li>Zero point if a historical cohort is used, considering prognostic factors at time zero which are not related to the primary research question for which the cohort is created, or in case of an ambispective design.</li> </ul>
	H Treatment in cohort is fully described/standardized
Outcome	<ul style="list-style-type: none"> <li>One point if treatment subsequent to inclusion into cohort, is fully described and standardized, or in case of no treatment is given, or if multi-variate correction for treatment is performed in analysis.</li> <li>Zero point if different treatment is given and if it is not clear how outcome is influenced by it, or if it is not clear whether any treatment is given.</li> </ul>
	I Relevant potential prognostic factors
	<ul style="list-style-type: none"> <li>One point if besides socio-demographic factors (age, gender) at least one other factor of the following is described at baseline: <ul style="list-style-type: none"> <li>health related factors</li> <li>personal factors</li> <li>external factors</li> </ul> </li> </ul>
	J Standardized or valid measurements
	<ul style="list-style-type: none"> <li>One point if at least one of the factors of I, excluding age and gender, are reported in a standardized or valid way (for example: questionnaire, structured interview, register, patient-status of health service).</li> </ul>
	K Data presentation of most important prognostic factors
Analysis	<ul style="list-style-type: none"> <li>One point if frequencies, or percentages, or mean (and standard deviation/confidence interval), or median (and Inter Quartile Range) are reported for the three most important factors of I, namely age, gender and at least one other factor, for the most important follow-up measurements.</li> </ul>
	L Relevant outcome measures
	<ul style="list-style-type: none"> <li>One point if at least one of the following outcome criteria is reported: social functioning, independent living, employment, daily life activities.</li> </ul>
Analysis	M Standardized or valid measurements
	<ul style="list-style-type: none"> <li>One point if one or more of the main outcome measures of L are reported in a standardized or valid way (for example: questionnaire, structured interview, registration, patient-status of occupational/insurance physician).</li> </ul>
	N Data presentation of most important outcome measures
	<ul style="list-style-type: none"> <li>One point if frequencies, or percentages, or mean (and standard deviation/confidence interval), or median (and Inter Quartile Range) are reported for one or more of the main outcome for the most important follow-up measurements.</li> </ul>
Analysis	O Appropriate univariate crude estimates
	<ul style="list-style-type: none"> <li>One point if univariate crude estimates (RR, OR, HRR) between prognostic factors separately and outcome are presented.</li> <li>Zero point if only p-values or wrong association values (Spearman, Pearson, sensitivity) are given, or if no tests are performed at all.</li> </ul>
	P Appropriate multivariate analysis techniques
	<ul style="list-style-type: none"> <li>One point if logistic regression analysis is used, or survival analysis for dichotomous outcomes, or linear regression analysis for continuous outcomes.</li> <li>Zero point if no multivariate techniques are performed at all.</li> </ul>

# CHAPTER 6



## Predictors of sustainable work participation of young adults with developmental disorders

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**ABSTRACT**

For individuals with autism spectrum disorders (ASD) and attention deficit hyperactivity disorder (ADHD) work participation is a challenge, as shown by their low employment rates. The aim of this study was to investigate which factors predict work participation, finding work as well as maintaining employment, of young adults with ASD as well as ADD. We obtained data on 563 individuals with ASD and/or ADD, aged 15-27 years. The follow-up period ranged from 1.25 to 2.75 years. Being male (for ADD), living independently (for ASD), expecting to be able to work fulltime (for ASD and ADD), high perceived support from parents and perceived positive attitude of parents regarding work (for ASD and ADD) and perceived positive attitude of social environment (for ADD) predicted finding work by the young adult, while being male (for ADD) and higher age (for ASD and ADD) and positive attitude of social environment regarding work (for ASD) predicted maintaining employment. Both personal and social factors predict work outcome and should be taken into account when supporting individuals with DD in their transition to work.

**KEYWORDS**

Developmental disorder, employment, autism spectrum disorder, ADHD

## INTRODUCTION

Developmental disorders (DD) are common and increasing, with autism spectrum disorders (ASD) and attention deficit hyperactivity disorders (ADHD) showing the most significant and successive increases over time (Boyle et al., 2011). In the last decade, the prevalence rate of ASD has increased considerably to 11% (Manning-Courtney et al., 2013; Tchaconas & Adesman, 2013); for ADHD prevalence rates of 3% to 12% are reported, with a 33% increase in prevalence from 1997–1999 to 2006–2008 (Al-Yagon et al., 2013; Boyle et al., 2011; De Graaf et al., 2008; Willcutt, 2012). Moreover, ASD and ADHD seem to be the two most disabling conditions among developmental disorders. However, in the past decade a discussion has arisen whether ASD and ADHD are two different disorders, as in the DSM-IV, or whether they are two different dimensions of the same developmental disorder. Several studies reported a considerable prevalence of ADHD symptoms, i.e. inattention and hyperactivity, in individuals with ASD (Fombonne et al., 2001; Gillberg & Billstedt, 2000; Lecavalier, 2006; Sverd, 2003). Furthermore, many individuals with ADHD share autistic traits and experience difficulty in social interaction, considered a significant element of ASD (Gjervan et al., 2012; Reiersen et al., 2008; Ronald et al., 2010). It is well-established that individuals diagnosed with ASD as well as ADHD suffer from problems in daily life functioning and that this hampers their work participation (Barkley et al., 2006; Boeltzig et al., 2008; Burke et al., 2010; Cimera & Cowan, 2009; De Graaf et al., 2008; Frazier et al., 2007; Gjervan et al., 2012; Halmoy et al., 2009; Kuriyan et al., 2013).

### Autism spectrum disorders and employment

Individuals with ASD experience impairments in social and communicative skills that limit their work functioning, leading to underutilization of skills and a limited range of work experiences (Burke et al., 2010; Cimera & Cowan, 2009). Among people with ASD, research showed employment rates from less than 10% to 50% (Billstedt et al., 2005; Engstrom et al., 2003; Shattuck et al., 2012; Wagner et al., 2005). These employment rates are considerably lower than the employment rate in the general population which exceeds 65% in most developed countries (Lysaght et al., 2012). Furthermore, individuals with ASD represent a significant percentage of the young adults claiming disability benefits; data of the Dutch Social Security Institute suggest that about 15% of the young disabled applying for a social security benefit has ASD (UWV, 2011). Moreover, individuals with ASD experienced unemployment and underemployment more often, worked far fewer hours than most of the other disability groups and the majority of jobs were unskilled and poorly paid (Burke et al., 2010; Cimera & Cowan, 2009; Eaves & Ho, 2008; Howlin et al., 2005; Taylor & Seltzer, 2011). When studying results of studies which examined variables related to employment among persons with autism, personal as well as social factors were reported. Limited cognitive ability, lack of drive, limited functional independence, low parental support and

institutionalization were found to hinder individuals with autism in their work outcomes (Holwerda et al., 2012). However, limited cognitive ability was the only strong personal predictor consistently found for work outcome for individuals with ASD.

### **Attention deficit disorders and employment**

For people with ADHD employment rate estimates ranged between 22 and 54% (Barkley et al., 2006; Gjervan et al., 2012; Halmoy et al., 2009). Individuals with ADHD also represent a significant percentage of the young adults claiming disability benefits (Gjervan et al., 2012; Halmoy et al., 2009). The Dutch Social Security Institute reported that 8% of the young disabled applying for a social security benefit was diagnosed with ADHD (UWV, 2011). Moreover, young adults with ADHD, who are employed, often attain lower status employment, earn lower wages, work part-time more often and experience more unstable employment situations compared to those without (Barkley et al., 2006; Gjervan et al., 2012; Halmoy et al., 2009; Kuriyan et al., 2013). Prospective longitudinal studies regarding ADHD and employment identified mostly factors related to diagnosis and treatment (Barkley et al., 2006; Gjervan et al., 2012; Halmoy et al., 2009; Hechtman, 1999; Kuriyan et al., 2013; Paternite et al., 1999). Few studies took personal factors, as education (Kuriyan et al., 2013) and IQ (Hechtman, 1999), and social factors, as parental involvement in school (Liptak et al., 2011), socioeconomic status and family adversity (Hechtman, 1999) into account. However, personal and social factors are frequently mentioned by professionals working with these individuals as important predictors for work outcome.

### **Sustainable employment**

Despite the poor employment outcomes noted above and the high and increasing number of disability claimants in different countries, part of these young adults diagnosed with ASD or ADHD are able to participate in work. As work participation is considered to be an increasingly important health outcome (WHO, 2001) and is associated with benefits which include learning of new skills, development of social relationships and being able to contribute to society (Carter & Lunsford, 2005; Stephens et al., 2005), it is important to stimulate young people with disabilities to be active in work. To be able to increase the work participation among individuals with DD, it is important to know which factors influence work outcome in this group and whether these factors are comparable for individuals with ASD and those with ADHD. Moreover, these prospective longitudinal studies mentioned above, assessed occupational outcomes as unemployment status (Paternite et al., 1999), number of jobs held (Barkley et al., 2006), percentage of job loss (Barkley et al., 2006) or occupational status (Hansen et al., 1999; Kuriyan et al., 2013; Liptak et al., 2011; Taylor & Seltzer, 2011). None of these focused on sustainable work participation. Sustainable work participation includes finding and maintaining employment over a period of time. As those working with ASD

or ADHD often have difficulty maintaining employment (*Biederman et al., 2008; Kuriyan et al., 2013; Shattuck et al., 2012*) and factors predicting finding work may differ from factors influencing maintaining employment, it is important to take sustainable work participation into account as well. Therefore, the aim of this study was to investigate which personal and social factors predict work participation, finding work as well as maintaining employment, of young adults with DD, and to examine whether the results for the subgroups of ASD and ADD converge or diverge.

## **METHODS**

### **Sampling and procedure**

This study is part of a cohort study called 'Young Disabled at Work' examining factors that predict work participation among young adults aged 15-27 years applying for a disability benefit at the Dutch Social Security Institute (SSI). In the Netherlands, the SSI is responsible for all work-ability assessments under social security regulations and provides a disability benefit to young adults with any disability who are not able to earn minimum wage independently. Participants eligible for the present study were recruited using registry data from the local SSI offices in the three northern regions in the Netherlands (Groningen, Friesland, Drenthe). For this study only participants with autism spectrum disorders (ASD) and attention deficit disorders (ADD) were included. Diagnosis was based on the insurance physician's (IP) indication of the primary and/or secondary diagnosis code (CAS code) responsible for the claimant's disability. This CAS-classification system has been derived from the ICD-10 and developed for use in occupational health and social security in the Netherlands (*Ouweland & Wouters, 1997*). Other primary or secondary diagnoses, in addition to autism spectrum disorders and attention deficit disorders were coded as co-morbid conditions. As the literature has shown that individuals with ASD without intellectual disability were more likely to be employed than individuals with ASD and intellectual disability (*Taylor & Seltzer, 2011*) and that a higher IQ facilitates a positive work outcome (*Billstedt et al., 2011; Cederlund et al., 2008; Eaves & Ho, 2008; Farley et al., 2009; Howlin, 2000; Howlin et al., 2004*), we also took intellectual disability (ID) into account. ID was based on the IP's classification of diagnosis.

Recruitment started at January 1, 2009 and ended at December 31, 2009 and took place at the beginning of the application process. This process generally lasts for several weeks, with the majority of final decisions taking place within two months (58.9%). The follow-up started in the quarter following the final decision of the SSI regarding the disability benefit. Because the inclusion period lasted one year, the follow-up period per individual ranged from one year and three months to two years and nine months and ended at September 30, 2011 for all participants. All twenty-one IPs employed by the SSI in the three regions participated in the study. During the claim assessment they

were asked to fill out a registration form, on which the primary diagnosis and co-morbid conditions of the claimant were filled out. If the claimant was not seen by the IP, he or she was excluded, because no information about medical condition and disability were available. Written consent was provided by all subjects and the Medical Ethics Committee of the University Medical Center Groningen, the Netherlands, approved recruitment, consent and field procedures prior to the study.

## **Measures**

### **Dependent factors**

The outcome measures, finding work and maintaining employment, were derived from the POLIS register data. The POLIS registry is a database, in which all Dutch workers are included that have earned any wage (from regular, supported or sheltered jobs) in the period concerned. Only paid work - for any number of hours - was included. In the period from December 2008 until September 2011 wage earning in the preceding month was assessed every quarter (twelve measurements). Using these data, we constructed two work outcome measures. Finding work was defined as work at any point during the follow-up. Maintaining employment in this study was defined as work for at least six consecutive months during the follow-up. Only wage earning following disability assessment was taken into account.

### **Demographics, independent personal and social factors**

Demographics (age and gender) were derived from SSI registers and diagnoses from the register forms filled in by the IPs. Preceding the disability assessment the participants were approached to fill out a questionnaire on personal and social factors. Because of the limited cognitive ability of part of the sample, it was not possible to use existing questionnaires. Therefore a questionnaire was developed using themes from the literature and items from other questionnaires which were adapted to be easily comprehensible. If needed, respondents could ask for help from parents or mentors when filling out the questionnaire.

The following five personal factors were included: educational level, self-esteem, self-knowledge, motivation and expectations regarding future work level.

Educational level was assessed by the question "Which education did you follow after primary school?" and divided into three educational groups: (1) Special secondary education / practical education (low), (2) Secondary education / vocational training (middle), and (3) High school / higher education (high).

Self-esteem was measured with six items, e.g. "I often feel insecure" and "I regularly worry about things", with response options true (0) / not true (1) (GGD *Flevoland*, 2003). This measure is used by all Dutch Community Health Centres for their assessment of youth public health in the municipalities.

The Cronbach's alpha coefficient was .701. The sum of all items was dichotomized into low self-esteem (scores 0-3) and high self-esteem (scores 4-6).

Self-knowledge was also measured with six items, e.g. "I know which work I can perform well" and "I know my strengths and weaknesses", with response options agree (1) / neutral (0) / do not agree (0). This measure was used before in a study regarding the pathway to work for young people with conduct disorders (*De Vos, 2008*). The Cronbach's alpha coefficient was .968. The sum of all items was dichotomized into poor self-knowledge (scores 0-3) and good self-knowledge (scores 4-6).

Motivation was measured with ten self-constructed items, e.g. "I like to earn (my own) money" and "I like to develop my skills", with response options true (1) / not true (0). The themes of the items were derived from another study regarding predictors for return to work (*Brouwer et al., 2011*) The Cronbach's alpha coefficient was .723. The sum of all items was dichotomized into low motivation (scores 0-7) and high motivation (scores 8-10).

Expectations of young disabled regarding work was measured with one self-constructed question "Do you think you are able to work in regular employment?" with response options yes, completely / yes, partly / no.

The following five social factors were included: living situation, perceived support from parents, perceived support in general, attitude of parent and attitude social environment regarding work for the young adult with DD.

Living situation was based on the respondent's response on two questions "What is your living situation?" with response options Parental home / Own place / Student home / Sheltered home / Institution or Hospital / Other and "Who is living there with you?". These questions were adapted from the 'Tracking Adolescents' Individual Lives' Survey' (TRAILS) questionnaire T4Youth based on the National Monitor Youth Health in the Netherlands (*RIVM, 2005*). Subsequently four mutually exclusive groups were constructed: (1) living independently with or without partner, (2) living with parents/family/foster family, (3) living in a supported/sheltered home, and (4) other living situations.

Perceived support from parents was measured by five self-constructed items, e.g. "My parents help me with problems" and "My parents support me when I am down", with response options true (1) / not true (0). These items were pilot-tested by 47 young adults with disabilities working in sheltered workshops and supported employment. The Cronbach's alpha coefficient was .784. The sum of all items was dichotomized in low perceived support (scores 0-3) and high perceived support (scores 4-5).

Perceived support in general was measured by six items, e.g. 'I have people to talk to' and "There are people I can always rely on", with response options true (1)/ not true (0). The Cronbach's alpha coefficient was .442. These items were adapted from the POLS Youth questionnaire (Permanent Study of Living Situation), which is a population based study, conducted every two years to gain understanding of the health and living situation of young

people from 12 to 29 years of age in the Netherlands (*Statistics Netherlands, 2005*). The sum of all items was dichotomized in low perceived support (scores 0-4) and high perceived support (scores 5-6).

Attitude of parents regarding work for young adult with DD was measured by one question "How important is it for your parents that you will find or retain work?" with response options very important / important / not important / I don't know / other". This measure was used before in a study regarding the pathway to work for young people with conduct disorders (*De Vos, 2008*). These responses were dichotomized into 'parent considers work important' and 'parent considers work not important or attitude is unknown'.

Attitude of social environment regarding work for young adult with DD was measured by one question "How important is it for your environment that you will find or retain work?" with response options very important / important / not important / I don't know / other. This measure was used before in a study regarding the pathway to work for young people with conduct disorders (*De Vos, 2008*). These responses were dichotomized into 'environment considers work important' and 'environment considers work not important or attitude is unknown'.

### **Statistical analyses**

Cox regression (survival) analyses were conducted in order to examine which factors predicted work-outcome. Separate analyses were conducted for finding work and maintaining employment. Subgroup analyses were conducted for the group with ASD and those with ADD separately. In the Cox regression, we entered the independent factors to the model simultaneously and performed a backward regression analysis. Interactions between intellectual disability (ID) (yes/no) and all the potential predictors were tested to examine whether predictors would differ for individuals with and without ID. An alpha of 0.05 was used for statistical tests in both models for the complete sample. For the subgroup analysis an alpha of 0.10 was used, because the number of cases in both groups was limited, especially with regard to maintaining employment. Because we had a considerable number of missing values for the personal and social covariates, we imputed missing data for these factors. Data were imputed using chained imputations (*Van Buuren, 2007*) with an imputation model consisting of all the personal and social potential predictors regressed on the following factors for which we had complete data: age, gender, diagnosis (ASD or ADHD or both), co-morbid developmental disability (yes/no), the factors indicating finding work and maintaining employment and the Nelson-Aalen estimator for the cumulative baseline hazard of the outcome (*White & Royston, 2009*). The multiple imputations (MI) were done separately for finding work and maintaining employment using the same imputation model except for the Nelson-Aalen estimators for the two separate work outcomes. Traceplots of means and sd's of imputed factors were checked for convergence. After we had observed convergence from the traceplots, we applied Rubin's rules to derive regression

coefficients for our potential predictors. In this process, we also examined whether the number of imputations influenced the results and found that results were stable after 50 imputations, which was used in the final analyses. Finally, complete case analyses were compared with the results from the imputed datasets to examine whether unexpected or extreme differences occurred. All analyses were conducted in STATA 12.1.

## **RESULTS**

### **Description of the sample**

The sample consisted of 879 individuals. We excluded 61 individuals from the analysis, because they already worked at baseline and thus were not at risk to enter into employment. Of the applicants with DD included in the study (n=818), 68.8 percent filled in the baseline questionnaire (n=563). These respondents did not differ from non-respondents with regard to age, gender and education, but did differ regarding living situation; respondents were more likely to live in residential placement or sheltered accommodation.

The cases included in the analysis consisted of 401 men (71.2%) and 162 women (28.8%), with a mean age of 19.4 years (SD 2.4), of whom 62 were younger than 18 years of age. Of the sample, 48.8% was still in the transition from school to work when applying for a disability benefit. Of the subjects, 31.6% found work in the 18 months following claim assessment (n=178), of whom 60.7% dropped out (n=108) and 39.3% (n=70) worked for at least six months. Most of the subjects had a middle educational background (53.4%) and the majority lived with parents or family (71.7%). Most individuals had an autism spectrum disorder (49.4%; n=278), 30.9% had ADHD (n=174) and 19.7% had both diagnoses (n=111). One hundred and thirty-nine subjects (24.7%) had two or more developmental disorders. Of the subjects, 62.7% had a poor self-knowledge; 81.1% were highly motivated (see table 1). The majority of subjects experienced high perceived support from parents (73.6%) and their social environment (82.3%) (see table 2).

### **Predictors of finding work**

The results of the survival analyses are presented in table 3. Six factors remained in the final model predicting finding work in individuals with DD, three personal and three social factors.

Gender, living situation and expectations regarding future work level were found as personal predictors for finding work. The Hazard Ratios (HR) indicate the size of the effect.

Males were 1.62 times more likely (HR=1.62, 95%CI 1.12 -2.36), and individuals living independently were 2.43 times more likely (HR=2.43, 95%CI 1.21-4.89) to find work compared to their counterparts. In addition, participants who expected to be able to work fulltime (HR=2.88, 95%CI 1.87-4.46) were more likely to find work than those expecting not to be able to work.

Table 1. Personal characteristics of respondents with developmental disorders

	Total N (%)	No work N (%)	Finding work <sup>a</sup> N (%)	Maintaining employment N (%)
<b>Work outcome</b>	563 (100%)	385 (68.4%)	108 (19.2%)	70 (12.4%)
<b>Gender (data SSI)</b>				
- Male	401 (100%)	261 (65.1%)	81 (20.2%)	59 (14.7%)
- Female	162 (100%)	124 (76.5%)	27 (16.7%)	11 (6.8%)
<b>Age (data SSI)</b>				
- 15-20 year	437 (100%)	303 (69.3%)	86 (19.7%)	48 (11.0%)
- 21-27 year	126 (100%)	82 (65.1%)	22 (17.5%)	22 (17.5%)
<b>Type developmental disorders (data SSI)</b>				
- Autism spectrum disorder	278 (100%)	193 (69.4%)	46(16.5%)	39 (14.0%)
- Attention deficit disorder	174 (100%)	110(63.2%)	44 (25.3%)	20 (11.5%)
- Both ASD and ADD	111 (100%)	82 (73.9%)	18 (16.2%)	11 (9.9%)
<b>Number of developmental disorders (data SSI)</b>				
- One developmental disorder	424 (100%)	286 (67.5%)	82 (19.3%)	56 (13.2%)
- Two or more developmental disorders	139 (100%)	99 (71.2%)	26 (18.7%)	14 (10.1%)
<b>Highest education <sup>b</sup> (n=537)</b>				
- Low	184 (100%)	126 (68.5%)	35 (19.0%)	23 (12.5%)
- Middle	287 (100%)	191 (66.6%)	58 (20.2%)	38 (13.2%)
- High	66 (100%)	47 (71.2%)	12 (18.2%)	7 (10.6%)
<b>Living arrangements <sup>b</sup> (n=515)</b>				
- Living independently (with or without partner)	48 (100%)	29 (60.4%)	12 (25.0%)	7 (14.6%)
- Living with parents/family/foster family	369 (100%)	242 (65.6%)	74 (20.1%)	53 (14.4%)
- Residential placement/sheltered accommodation	71 (100%)	57 (80.3%)	7 (9.9%)	7 (9.9%)
- Other living situation	27 (100%)	19 (70.4%)	7 (25.9%)	1 (3.7%)
<b>Expectations future work level<sup>b</sup> (n=563)</b>				
- Completely able to work in competitive employment	74 (100%)	29 (39.2%)	30 (40.5%)	15 (20.3%)
- Partly able to work in competitive employment	218 (100%)	149 (68.3%)	42 (19.3%)	27 (12.4%)
- Not able to work in competitive employment	184 (100%)	142 (77.2%)	19(10.3%)	23 (12.5%)
- Unknown	87 (100%)	65 (74.7%)	17 (19.5%)	5 (5.7%)
<b>Self-esteem <sup>b</sup> (n=488)</b>				
- Low self-esteem	216 (100%)	143 (66.2%)	45 (20.8%)	28 (13.0%)
- High self-esteem	272 (100%)	187 (68.8%)	50 (18.4%)	35 (12.9%)
<b>Self-knowledge <sup>b</sup> (n=496)</b>				
- Poor self-knowledge	311 (100%)	216 (69.5%)	51 (16.4%)	44 (14.1%)
- Good self-knowledge	185 (100%)	118 (63.8%)	46 (24.9%)	21 (11.4%)
<b>Motivation <sup>b</sup> (n=492)</b>				
- Low motivation	93 (100%)	69 (74.2%)	15 (16.1%)	9 (9.7%)
- High motivation	399 (100%)	258 (64.7%)	84 (21.1%)	57 (14.3%)

<sup>a</sup> Individuals finding work but not maintaining employment for at least 6 months are described in this column.

<sup>b</sup> Self-report by individuals with DD.

Table 2. Social characteristics of respondents with developmental disorders

Social factors	Total	No work	Finding work <sup>a</sup>	Maintaining employment
	N (%)	N (%)	N (%)	N (%)
<b>Perceived support from parents <sup>b</sup> (n=497)</b>				
- Low perceived support	131 (100%)	80 (61.1%)	36 (27.5%)	15 (11.5%)
- High perceived support	366 (100%)	255 (69.7%)	61 (16.7%)	50 (13.7%)
<b>Perceived support in general <sup>b</sup> (n=462)</b>				
- Low perceived support	82 (100%)	57 (69.5%)	17 (20.7%)	8 (9.8%)
- High perceived support	380 (100%)	254 (66.8%)	75 (19.7%)	51 (13.4%)
<b>Attitude of parents regarding work <sup>b</sup> (n=501)</b>				
- Considers work important	391 (100%)	249 (63.7%)	84 (21.5%)	58 (14.8%)
- Considers work not important or unknown	110 (100%)	90 (81.8%)	14 (12.7%)	6 (5.5%)
<b>Attitude of social environment regarding work <sup>b</sup> (n=498)</b>				
- Considers work important	291 (100%)	182 (62.5%)	60 (20.6%)	49 (16.8%)
- Considers work not important or unknown	207 (100%)	152 (73.4%)	39 (18.8%)	16 (7.7%)

<sup>a</sup> Individuals finding work but not maintaining employment for at least 6 months are described in this column.

<sup>b</sup> Self-report by individuals with DD.

Perceived support from parents and attitude of parents regarding work by young adults with DD were found as social factors predicting finding work. Individuals who experienced high parental support were less likely to find work than individuals with a low perceived support from parents (HR=0.67, 95%CI 0.47-0.95), whereas those whose parents considered work important for their young adult (HR=1.99, 95%CI 1.19-3.31) were more likely to find work compared to their counterparts.

In the subgroup analysis for individuals with ASD, living situation, expectations regarding future work level and motivation were found as predictors for finding work. Individuals with ASD living independently (HR=5.57, 90%CI 2.25-13.75) or living with parents or family (HR=2.30, 90%CI 1.13-4.66), those expecting to be able to work fulltime (HR=2.96, 90%CI 1.78-4.93) and those who were highly motivated (HR=2.18, 90%CI 1.15-4.14) were more likely to find work compared to their counterparts. In the subgroup analysis for individuals with ADD, gender, expectations regarding future work level and attitude of social environment regarding work were found as predictors for finding work. Males (HR=2.92, 90%CI 1.67-5.10), those expecting to be able to work fulltime (HR=2.41, 90%CI 1.30-4.47) and those whose social environment considered work important (HR=1.80, 90%CI 1.10-2.98) were more likely to find work compared to their counterparts.

No significant interactions between the presence of intellectual disability and the potential predictors were found.



### **Predictors of maintaining employment**

Three factors remained in the final model predicting maintaining employment in individuals with DD, two personal and one social factor (see table 3). Being male (HR=2.30, 95%CI 1.20-4.38) and higher age (HR=1.10, 95%CI 1.01-1.20) were the two personal factors predicting maintaining employment. Positive attitude of social environment regarding work (HR=2.45, 95%CI 1.40-4.32) was the social factor predicting maintaining employment.

In the subgroup analysis for individuals with ASD, living situation (HR=4.22, 90%CI 1.08-16.47) and positive attitude of social environment regarding work (HR=2.50, 90%CI 1.33-4.70) were the two factors predicting maintaining employment. In the subgroup analysis for individuals with ADD, gender (HR=5.26, 90%CI 1.54-17.93) was the only factor predicting maintaining employment.

No significant interactions between the presence of intellectual disability and the potential predictors were found.

### **Comparisons with complete case analyses**

Cox regression analyses on complete cases using all potential predictors (Method Enter) yielded coefficients of the same relative magnitude and direction as compared to the multiple imputation (MI) Cox regression analyses with all potential predictors for finding and maintaining employment. The largest deviation was seen for attitude of parents regarding work, which was not related to maintaining employment in the complete case analysis (HR 0.99 95%CI: 0.35-2.80), whereas it was positively (although not statistically significantly) related in the MI analysis (HR 1.87, 95%CI: 0.71-4.91).

### **DISCUSSION AND CONCLUSION**

In this study we found that several factors predicted finding and maintaining work, one of which overlapped for both outcomes, whereas most only predicted one of the outcomes. Being male was the only factor predicting both finding and maintaining work and this applied to the total sample as well as the sample with ADD, but not the ASD-sample. Living independently, expectations to be able to work fulltime and lower perceived parental support and positive attitude of parents regarding work were only related to finding work, whereas higher age and positive attitude of environment regarding work predicted maintaining employment.

In contrast to the premise stated in the introduction, that ASD and ADHD may represent two dimensions of the same developmental disorder, our results suggest that although the disorders may have traits in common and may even result in the same limited vocational outcomes, the factors influencing this work outcome for ASD and ADD differ. Living situation and motivation appeared to be only influential for individuals with ASD, while gender only influenced work outcome for individuals with ADD.

Previous studies also found that men were more likely to participate in work compared to women (Benz, Doren, & Yovanoff, 1998; Coutinho, Oswald, & Best, 2006). In our sample 37% of the men were working compared to 28% of the women. In our subgroup analyses, we found gender only predicting work outcome for individuals with ADD, not for those with ASD. As the symptoms of the disorder may be expressed differently in women and men, this may cause a different developmental path for both genders. Several studies mentioned that self-esteem in young women with disabilities is often lower than in their male counterparts, influencing poorer employment outcomes (Benz et al., 1998; Fulton & Sabornie, 1994). This is confirmed by our study: 32% of the women had high self-esteem compared to 48% of the men ( $p=0.001$ ). This might also be the reason that more females in our study (44%) expected not to be able to work than men (34%). Another hypothesis is that girls may receive another kind of support from their parents, who may want to protect their girls, being afraid the many stimuli in the work place may be detrimental to their daughters health. Moreover, more women with disabilities than men are married and experience early parenting responsibilities, perhaps preventing many of them to be engaged in employment (Benz et al., 1998; Coutinho et al., 2006; Fulton & Sabornie, 1994; Wagner, 1992). This is corroborated by our study results that showed that significantly more women than men were living with partner and may have had children. Finally, literature suggests that the disadvantage of young women with disabilities on the labour market may also result from the lack of appropriate services they receive during their education (Benz et al., 1998; Fulton & Sabornie, 1994; Wagner, 1992). Women may need different services and vocational training for the transition into independent adulthood (Fulton & Sabornie, 1994; Wagner, 1992).

Results showed that expectations concerning work outcomes of individuals with DD themselves, for the complete sample as well as for the separate groups of individuals with ASD or ADD, were a strong predictor of finding work. When individuals expected themselves to be able to work fulltime, they were more likely to find work than individuals who did not expect themselves to be able to work. These expectations may be realistic and therefore predict work outcome. But, it might also be that optimistic expectations stimulate the individual to search for and find work. Once employed other, e.g. work-related, factors may influence the effect of expectations on maintaining employment. This is in accordance with the finding, that individuals with ADHD had a greater job instability than their peers, because of being fired, being laid off or quitting because of dislike (Kuriyan et al., 2013).

Besides personal factors we found that several social factors are important predictors for finding and maintaining employment for individuals with DD. Other research has indicated that family members and friends influence the career of individuals with disabilities by role modelling and sharing

information regarding their own occupations and their expectations for the individual (Eisenman, 2007). As described in the literature, parents play a major role in the transition to work for individuals with DD (Howlin, 2000; Howlin et al., 2004). Parents may stimulate their adolescent in finding work, but also be an intermediate in negotiating a job with an employer. Besides providing positive support, parents may also overprotect their child, being wary of detrimental effects of work for their young adult with DD. This may explain our counterintuitive results on parental support, i.e. lower perceived social support from parents has been found to be a predictor for finding work. When comparing the level of perceived support from parents with diagnosis and presence of intellectual disability, we found that diagnosis was not related to the level of perceived social support of parents, but intellectual disability was. Individuals with DD and an intellectual disability reported higher perceived support of parents, than individuals with DD, but no intellectual disability. As the literature has shown that individuals with ASD and intellectual disability were less likely to be employed than individuals with ASD without intellectual disability (Taylor & Seltzer, 2011), this may also explain our finding.

In contrast to the results for the complete sample, we did not find a parental influence on individuals with ASD or ADD in the subgroup analysis.

In our study we found that a positive attitude from the social environment (e.g. friends and neighbours) predicted maintaining employment for the complete sample as well as for individuals with ASD. In contrast, a positive attitude from the social environment predicted finding work for individuals with ADD. In literature it has been confirmed that friends and neighbours can also be a role model for individuals with DD in showing employment as a valued aspect of adulthood (Jennes-Coussens et al., 2006). Furthermore, as the social network of working individuals with DD broadens (Ridley & Hunter, 2006), their social environment may also encourage them to maintain employment.

### **Strengths and limitations of the study**

The strengths of this study are the size of our sample, the longitudinal design and the use of register data for work outcome, measured quarterly, allowing accurate assessment of work outcome during the follow-up for the complete sample.

However, some limitations must be taken into account as well. First, we did not know whether individuals that were still in education at the start of the study, finished their education during the follow-up and therefore some may not have been able to participate in work during the follow-up because of this. However, we know that more than half of the subjects (51.2%) had left school at the start of the study. We hypothesize that because of the generally low educational attainment of individuals with DD, the others will have left school during the follow-up and will have been available for the labour market as well.

Work outcome was measured quarterly, so we may not have captured work performed in the months in between. Individuals may have found work, but not maintained it until the following measurement. With regard to maintaining employment, individuals may have found work, lost their job, but found new work before the following measurement. In this case sustainability is suggested, but in reality transitions may have taken place. However, it seems reasonable that the vast majority of individuals did not find more than two subsequent jobs in six months, so the measurement error was presumably small.

Because of the limited cognitive ability of part of the sample, a questionnaire was developed using themes from the literature and items from other questionnaires which were adapted to be easily comprehensible. In general the Cronbach's alpha coefficients were adequate, ranging from .701 to .968. However, the Cronbach's alpha coefficient for perceived support in general was .442 even though these items were adapted from the population based survey POLS Youth (Permanent Study of Living Situation). We presume the low Cronbach's alpha is related to the difficulty individuals with DD generally have with social contacts (*Holwerda et al., 2012; Howlin et al., 2004; Jennes-Coussens et al., 2006*).

Finally, although we had a considerable sample size, only a relatively small number of individuals found and maintained employment. Therefore, we used an alpha of 0.10 in our subgroup analyses in order to increase our statistical power. However, this increased the probability of a type I error which might have resulted in false positive findings.

## **Conclusion**

In conclusion, the results from our study indicate that both personal and social factors are important in predicting work outcome, and that predictors for finding work differ substantially from predictors for maintaining employment. Living situation and motivation appeared to be only influential for individuals with ASD, while gender only influenced work outcome for individuals with ADD. Besides socio-demographic characteristics (age, gender, living situation) we found that expectations regarding future work level by the DD-individuals themselves is an important predictor for finding work. As this factor is a modifiable factor, it is important for professionals to take the expectations of individuals with DD into account when supporting these individuals to find work. Especially negative expectations may hinder individuals to find work and professionals may encourage these individuals to focus on acquired skills and positive traits to enhance their chances to find work. As the social context of individuals with DD seem to play a major role in finding and maintaining work, we suggest they need to be taken into account as well by professionals working with individuals with DD in their transition to find work. Moreover, adequate support should be organized for the working individual with DD to be able to maintain employment.

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# CHAPTER 7

## Predictors of work participation of young adults with mild intellectual disabilities

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**ABSTRACT**

Individuals with intellectual disabilities (ID) are three to four times less often employed compared to their non-disabled peers. Evidence for factors associated with work participation of young adults with ID is limited. Furthermore, studies on predictors for sustainable work participation among young adults with ID is lacking altogether. Therefore, the aim of this study was to investigate which factors predict finding as well as maintaining employment of young adults with mild ID. We obtained data on 735 young adults with mild ID, aged 15-27 years, applying for a disability benefit. The follow-up period ranged from 1.25 to 2.75 years. Motivation, expectations regarding future work level and living situation predicted finding work as well as maintaining employment for at least 6 months. In this study, especially personal factors were influential in predicting work outcome and may be suitable factors to include in interventions.

## INTRODUCTION

The participation rates of young adults with intellectual disabilities (ID) range from 10% to 40%, which is considerably lower than the participation rates of their peers without disability (Ireys *et al.*, 1996; Lysaght *et al.*, 2012a; Rose *et al.*, 2005; WHO & World Bank, 2011). Moreover, it has been shown that individuals with ID were 3–4 times less often employed compared to their non-disabled peers, that they were less likely to be competitively employed and more likely to work in sheltered work or segregated settings than those with other disabilities (Verdonschot *et al.*, 2009a). It also has been found that individuals with ID tend to work in entry level positions, earn lower wages and work fewer hours than their non-disabled peers (Jahoda *et al.*, 2008; Kirsh *et al.*, 2009; Lysaght *et al.*, 2012a).

Although research suggests that individuals with ID can be a potentially valuable resource for the workforce as they are typically stable, loyal and competent employees, in daily living it is apparently a struggle for them to find and to maintain a job (Kirsh *et al.*, 2009; Lysaght *et al.*, 2012a). In the Netherlands young adults with ID are mostly educated in special needs education classes. These special needs schools provide vocational training and internships for young adults with ID in the final years at school and appropriate job placements in the transition from school to work.

Individuals with ID often need continuous assistance and support in the transition from school to work as well as on the job (Lindsay, 2011; Verdonschot *et al.*, 2009a; Verdonschot *et al.*, 2009b) to be able to develop and maintain their work skills. The lack of work and of necessary support services can make these people overly dependent on family members or social protection (Davies & Beamish, 2009; Dixon & Reddacliff, 2001; Donnelly *et al.*, 2010).

Many individuals with ID desire to participate in work (Donnelly *et al.*, 2010; Eggleton *et al.*, 1999), which provides them with opportunities for financial independence and independent living, as well as a structured life and meaningful social participation (Dixon & Reddacliff, 2001; Eggleton *et al.*, 1999; Grant, 2008; Jahoda *et al.*, 2008; Lysaght *et al.*, 2012a; Lysaght *et al.*, 2012b). Work allows them to have contact with other people besides family and friends (Dixon & Reddacliff, 2001; Donnelly *et al.*, 2010; Eggleton *et al.*, 1999; Grant, 2008; Jahoda *et al.*, 2008; Lysaght *et al.*, 2012a; Lysaght *et al.*, 2012b) and work may help to build their self-confidence and develop their skills (Eggleton *et al.*, 1999; Grant, 2008). A review on the socio-emotional impact of supported employment on individuals with ID, found competitive employment was positively related to quality of life, well-being and autonomy (Jahoda *et al.*, 2008). This was confirmed by other studies (Claes *et al.*, 2012; Eggleton *et al.*, 1999; Kober & Eggleton, 2005). However, competitive employment was not related to an increasing sense of social belonging and community integration of individuals with ID (Eggleton *et al.*, 1999; Jahoda *et al.*, 2008). In contrast, Kober & Eggleton (2005) found that competitively employed individuals with ID scored higher on social belonging and community integration than their counterparts in sheltered employment.

To be able to increase the employment rate of young adults with ID and the effectiveness of support programmes it is important to know which factors facilitate or hinder work participation. Knowledge of prognostic factors for sustainable work participation could provide important input for interventions in the transition from school to work and for support services while working.

Personal and social factors (e.g. motivation, self-esteem, family involvement and social support) have been stated in both reviews as well as qualitative studies as being essential in securing employment for individuals with ID (Eisenman, 2003; Foley et al., 2012; Timmons et al., 2011). Motivation has been well established in the literature (Foley et al., 2012; Timmons et al., 2011) and has been often mentioned by practitioners to influence employment outcomes. Low self-esteem in individuals with disabilities has been found to decrease the chance of employment (Eisenman, 2003). Research also highlights the role of family members in the transition from school to work, offering career-related advice, helping to find jobs, shaping aspirations and offering practical and moral support to maintain employment (Eisenman, 2003; Timmons et al., 2011). However, only three studies had employment status as their primary outcome (Dunham et al., 2000; Martorell et al., 2008; Rose et al., 2005). Furthermore, work status in these studies was assessed by asking if the subjects had found a job or were currently working. No studies on sustainability of employment, i.e. finding and maintaining a job for a specified period of time, in this population were found. As a result, insight in predictors for sustainable employment among young adults with ID is limited. Sustainability of employment is important in this group as young adults with ID are vulnerable to changes and have better chances to develop their working skills in a stable work environment. As factors influencing finding work by individuals with ID may differ from factors influencing maintaining employment, it is important to take sustainability of employment into account as well. Besides the lack of appropriate work outcome measures, previous studies have been cross-sectional or retrospective in design (Davies & Beamish, 2009; Donnelly et al., 2010; Dunham et al., 2000; Martorell et al., 2008; Rose et al., 2005). Other studies have been explorative and qualitative (Dixon & Reddacliff, 2001; Donnelly et al., 2010; Timmons et al., 2011). No prospective longitudinal studies are known to us, meaning prognostic factors for work participation in this group are unknown.

Therefore, the aim of this study was to investigate which factors predict sustainable work participation, finding as well as maintaining employment, of young adults with mild ID.

## **METHODS**

### **Sampling and procedure**

This study is part of a cohort study 'Young Disabled at Work' examining factors that predict work participation among young adults, aged 15-27 years, who applied for a disability benefit at the Dutch Social Security Institute (SSI). The SSI is responsible for all work-ability assessments under social security regulations and provides a disability benefit to young adults with any disability who are not able to earn minimum wage level independently. For a detailed description of the work ability assessment in the Netherlands, see Holwerda et al. (2012). Participants eligible for the present study were recruited using registry data from the local SSI offices in the three northern regions in the Netherlands (Groningen, Friesland, Drenthe). For this study only participants with mild intellectual disabilities were included. Individuals with moderate or severe ID were excluded, because they were often deemed to have no ability to work according to the insurance physician (IP). Diagnosis was based on the IP's indication of the primary or secondary diagnosis code (CAS-codes) responsible for the claimant's disability. This classification system (CAS) has been derived from the ICD-10 and developed for use in occupational health and social security in the Netherlands (*Ouwehand & Wouters, 1997*). In this study applicants with diagnoses coded as chromosomal abnormalities, other congenital anomalies or other developmental disorders resulting in a mild or borderline intellectual disability, were eligible for the study. The ID-level was determined by the insurance physician, based on IQ, personal and social functioning and level of support needed.

Recruitment started at January 1st 2009 and ended at 31st December 2009. The follow-up period started at December 31st, 2008 and ended at September 30th, 2011. Because the inclusion lasted one year, the follow-up differed for the individuals in the study and started in the quarter following the disability assessment at the SSI. The follow-up period per individual ranged from one year and three months to two years and nine months. During the claim assessment insurance physicians of the SSI were asked to fill out a registration form, on which the diagnosis and possible co-morbid conditions were filled out. Preceding the disability assessment the participants were approached to fill in a questionnaire on personal and social factors. Written consent was provided by all subjects and the Medical Ethics committee of the University Medical Center Groningen, the Netherlands, approved recruitment, consent and field procedures prior to the study.

## Measures

### **Finding and maintaining employment (outcome variables)**

The outcome measures, finding work and sustainable employment, were derived from the POLIS register data. The POLIS registry is a database, in which all Dutch workers are included that have earned any wage (from regular, supported or sheltered jobs) in the period concerned. Only paid work - for any number of hours - was included. In the period from December 2008 until September 2011 wage earning in the preceding month was assessed every quarter (twelve measurements). Using these data, we constructed the two work outcome measures. Finding work was defined as work at any point during the follow-up. Maintaining work was defined as work for at least six consecutive months during the follow-up. Only wage earning following disability assessment was taken into account.

### **Personal and social factors (independent factors)**

Age and gender were derived from SSI registers.

Occurrence of co-morbid condition was based on the IP's indication of a primary and/or secondary diagnosis code (CAS code), in addition to the mild intellectual disability.

Education was self-reported by the respondent on the question "Which education did you follow after primary school?" with the following response options: Special Secondary Education / Practical Education / Secondary education / Vocational training / Highschool / Higher Education / Other.

Self-esteem was measured with six items, e.g. "I often feel insecure" and "I regularly worry about things", with response options true / not true (GGD Flevoland, 2003). A sum score was calculated ranging from 0 (low self-esteem) to 6 (high self-esteem). This sum score was dichotomized in low self-esteem (scores 0 to 3) and high self-esteem (scores 4 to 6).

Self-knowledge was with six items, e.g. "I know which work I can perform well" and "I know my strengths and weaknesses", with response options agree / neutral / do not agree (De Vos, 2008). A sum score was calculated ranging from 0 (poor self-knowledge) to 6 (excellent self-knowledge). This sum score was dichotomized in poor self-knowledge (scores 0 to 3) and good self-knowledge (scores 4 to 6).

Motivation was measured with ten self-constructed items, e.g. "I like to earn (my own) money" and "I like to develop my skills", with response options true / not true. A sum score was calculated ranging from 0 (not motivated) to 10 (highly motivated). This sum score was dichotomized in low motivation (scores 0 to 7) and high motivation (scores 8 to 10).

Expectation of young adult with ID regarding future work level was measured with one self-constructed question "Do you think you are able to work in regular employment?" with response options yes, completely / yes, partly / no.

Living situation was based on the respondent's response on two questions (1) "What is your living situation?" with response options Parental home /

Own place / Student home / Sheltered home / Institution or Hospital / Other and (2) "Who is living there with you?". These questions were adapted from the 'Tracking Adolescents' Individual Lives' Survey' (TRAILS) questionnaire T4Youth based on the National Monitor Youth Health in the Netherlands (RIVM, 2005). Subsequently four mutually exclusive groups were constructed: (1) living independently with or without partner, (2) living with parents/family/foster family, (3) living in a supported/sheltered home, and (4) other living situations.

Perceived support from parents was measured by five self-constructed items, e.g. "My parents help me with problems" and "My parents support me when I am down", with response options true / not true. A sum score was calculated ranging from 0 (no perceived support) to 5 (high perceived support). This sum score was dichotomized in low perceived support (scores 0 to 3) and high perceived support (scores 4 to 5).

Perceived support in general was measured by six items, e.g. 'I have people to talk to' and "I feel isolated from others", with response options true / not true. These items were adapted from the POLS Youth questionnaire (Permanent Study of Living Situation) (*Statistics Netherlands, 2005*). A sum score was calculated ranging from 0 (no perceived support) to 6 (high perceived support). This sum score was dichotomized in low perceived support (scores 0 to 4) and high perceived support (scores 5 to 6).

Attitude of parents regarding work for young adult with ID was measured by one question "How important is it for your parents that you will find or retain work?" with response options very important / important / not important / I don't know / other (*De Vos, 2008*). These responses were recoded into a dichotomized score with two categories 'parent considers work important' and 'parent considers work not important or attitude is unknown'. Attitude of social environment regarding work for young adult with ID was measured by one question "How important is it for your environment that you will find or retain work?" with response options very important / important / not important / I don't know / other (*De Vos, 2008*). These responses were recoded into a dichotomized score with two categories 'environment considers work important' and 'environment considers work not important or attitude is unknown'.

### Statistical Analyses

Cox regression (survival) analyses were conducted in order to examine which factors predicted work-outcome. Separate analyses were conducted for finding employment and for maintaining employment. In the Cox regression, we entered the four potential personal predictors (self-esteem, self-knowledge, motivation and expectation regarding future work level) and the five potential social predictors (living situation, perceived support from parents, perceived support in general, attitude of parent and attitude of social environment regarding work for young adult with ID) to the model simultaneously and performed a backward regression analysis. Because we

had a considerable number of missing values for the covariates, we decided to impute missing data for these variables. Data were imputed using chained imputations (*Van Buuren, 2007*) with an imputation model consisting of all the potential predictors and comorbidity regressed on the following variables for which we had complete data: age, gender, the variables indicating finding work and maintaining employment and the Nelson-Aalen estimator for the cumulative baseline hazard of the outcome (*White & Royston, 2009*). The multiple imputations were done separately for finding work and sustainable employment using the same imputation model except for the Nelson Aalen estimators for the two separate outcomes (finding work and sustainable employment). Traceplots of means and sd's of imputed variables were checked for convergence. After we had observed convergence from the traceplots, we applied Rubin's rules to derive regression coefficients for our potential predictors. In this process, we also examined whether the number of imputations influenced the results and found that results were stable after 50 imputations, which is what we used in the final analyses. Finally, complete case analyses were compared with the results from the imputed datasets to examine whether unexpected or extreme differences occurred. An alpha of 0.05 was used for all statistical tests. The survival analyses were conducted in STATA version 12.1.

## **RESULTS**

### **Description of the sample**

Administrative data about gender and age was available for all disability claimants with mild ID ( $n=936$ ). We excluded 40 individuals from the analyses, because the severity of their mental retardation was unknown. Another 99 individuals were excluded from the analysis, because they already worked at baseline and thus were not at risk to find work. Of the applicants included in the study ( $n=797$ ), 92.2% filled out a questionnaire ( $n=735$ ). These respondents did not differ from non-respondents with regard to age, but did differ regarding gender; more non-respondents were males.

The cases included in the analysis consisted of 427 men (58.1%) and 308 women (41.9%), with a mean age of 18.5 years (SD 1.9). Of the subjects, 67.5% ( $n=496$ ) had not found work during the follow-up, 32.6% found work ( $n=239$ ), of whom 17.6% dropped out ( $n=129$ ) and 15.0% ( $n=110$ ) worked for at least six months. Most of the subjects had a low educational background (68.1%) and the majority lived with parents or family (76.8%). Of the subjects, 36.9% had one and 19.5% had two or more comorbid conditions. Developmental disorders were the most common comorbid condition (37.7%). Of the subjects, 58.2% had a high self-esteem and 92.6% were highly motivated. Almost one in three subjects experienced low perceived support from parents (30.1%).

**Table 1. Personal characteristics of respondents with mild intellectual disabilities**

	Total	No work	Finding work <sup>a</sup>	Sustainable employment
	N (%)	N (%)	N (%)	N (%)
<b>Work outcome</b>	735 (100.0%)	496 (67.5%)	129 (17.6%)	110 (15.0%)
<b>Gender (data SSI)</b>				
- Male	427 (58.1%)	276 (55.6%)	73 (56.6%)	78 (70.9%)
- Female	308 (41.9%)	220 (44.4%)	56 (43.4%)	32 (29.1%)
<b>Age (data SSI)</b>				
- 15-20 year	657 (89.4%)	436 (87.9%)	120 (93.0%)	101 (91.8%)
- 21-27 year	78 (10.6%)	60 (12.1%)	9 (7.0%)	9 (8.2%)
<b>Comorbidity (n=735)</b>				
- Psychiatric & Developmental Disorders	324 (44.1%)	235 (47.4%)	57 (44.2%)	32 (29.1%)
- Somatic diseases	90 (12.2%)	60 (12.1%)	15 (11.6%)	15 (13.6%)
- No comorbidity	321 (43.7%)	201 (40.5%)	57 (44.2%)	63 (57.3%)
<b>Number of comorbid conditions (n=735)</b>				
- Two or more comorbid conditions	143 (19.5%)	107 (21.6%)	22 (17.1%)	14 (12.7%)
- One comorbid condition	271 (36.9%)	188 (37.9%)	50 (38.8%)	33 (30.0%)
- No comorbidity	321 (43.7%)	201 (40.5%)	57 (44.2%)	63 (57.3%)
<b>Highest education<sup>b</sup> (n=530)</b>				
- Special Secondary Education	132 (24.9%)	106 (30.6%)	22 (22.4%)	4 (4.7%)
- Practical Education	229 (43.2%)	130 (37.6%)	42 (42.9%)	57 (66.3%)
- Secondary education	62 (11.7%)	44 (12.7%)	8 (8.2%)	10 (11.6%)
- Vocational training	90 (17.0%)	51 (14.7%)	25 (25.5%)	14 (16.3%)
- High school	4 (0.8%)	4 (1.2%)	0 (0.0%)	0 (0.0%)
- Higher Education (College/University)	5 (0.9%)	4 (1.2%)	0 (0.0%)	1 (1.2%)
- Other	8 (1.5%)	7 (2.0%)	1 (1.0%)	0 (0.0%)
<b>Living situation<sup>b</sup> (n=508)</b>				
- Living independently (with or without partner)	36 (7.1%)	25 (7.5%)	5 (5.6%)	6 (7.1%)
- Living with parents/family/foster family	390 (76.8%)	242 (72.5%)	74 (82.2%)	74 (88.1%)
- Residential placement/sheltered accommodation	66 (13.0%)	57 (17.1%)	8 (8.9%)	1 (1.2%)
- Other living situation	16 (3.1%)	10 (3.0%)	3 (3.3%)	3 (3.6%)
<b>Expectation future work level<sup>b</sup> (n=735)</b>				
- Completely able to work in competitive employment	106 (14.4%)	47 (9.5%)	32 (24.8%)	27 (24.5%)
- Partly able to work in competitive employment	196 (26.7%)	125 (25.2%)	40 (31.0%)	31 (28.2%)
- Not able to work in competitive employment	156 (21.2%)	132 (26.6%)	8 (6.2%)	16 (14.6%)
- Unknown	277 (37.7%)	192 (38.7%)	49 (38.0%)	36 (32.7%)
<b>Self-esteem<sup>b</sup> (n=471)</b>				
- Low self-esteem	197 (41.8%)	148 (48.1%)	25 (29.1%)	24 (31.2%)
- High self-esteem	274 (58.2%)	160 (51.9%)	61 (70.9%)	53 (68.8%)

<sup>a</sup> Individuals finding work in this table have not been able to retain work for 6 months

<sup>b</sup> Self-report by individuals with mild ID

**Table 1. Personal characteristics of respondents with mild intellectual disabilities (continued)**

	Total	No work	Finding work <sup>a</sup>	Sustainable employment
	N (%)	N (%)	N (%)	N (%)
<b>Self-knowledge <sup>b</sup> (n=490)</b>				
- Poor self-knowledge	255 (52.0%)	175 (55.4%)	43 (47.3%)	37 (44.6%)
- Good self-knowledge	235 (48.0%)	141 (44.6%)	48 (52.7%)	46 (55.4%)
<b>Motivation <sup>b</sup> (n=484)</b>				
- Low motivation	36 (7.4%)	33 (10.5%)	2 (2.2%)	1 (1.2%)
- High motivation	448 (92.6%)	282 (89.5%)	87 (97.8%)	79 (98.8%)
<b>Perceived support from parents <sup>b</sup> (n=564)</b>				
- Low perceived support	170 (30.1%)	119 (31.4%)	26 (25.0%)	25 (30.9%)
- High perceived support	394 (69.9%)	260 (68.6%)	78 (75.0%)	56 (69.1%)
<b>Perceived support in general <sup>b</sup> (n=541)</b>				
- Low perceived support	91 (16.8%)	67 (18.2%)	14 (14.4%)	10 (13.2%)
- High perceived support	450 (83.2%)	301 (81.8%)	83 (85.6%)	66 (86.8%)
<b>Attitude of parents regarding work <sup>b</sup> (n=495)</b>				
- Considers work important	410 (82.8%)	251 (77.5%)	85 (93.4%)	74 (92.5%)
- Considers work not important or unknown	85 (17.2%)	73 (22.5%)	6 (6.6%)	6 (7.5%)
<b>Attitude of social environment regarding work <sup>b</sup> (n=496)</b>				
- Considers work important	328 (66.1%)	202 (62.2%)	67 (73.6%)	59 (73.8%)
- Considers work not important or unknown	168 (33.9%)	123 (37.8%)	24 (26.4%)	21 (26.3%)

<sup>a</sup> Individuals finding work in this table have not been able to retain work for 6 months

<sup>b</sup> Self-report by individuals with mild ID

## Predictors of work participation in young adults with mild ID

The results of the survival analyses are presented in table 2.

The final model regarding finding work consisted of the following predictors: living situation, motivation, and expectation regarding future work level. Individuals living with parents or family or living independently were three times more likely to find work than individuals living in residential placement or sheltered accommodation (HR=2.95, 95%CI 1.20-7.21 and HR=2.96, 95%CI 1.50-5.81 respectively). Highly motivated individuals were three times more likely to find work than less motivated individuals (HR=3.47, 95%CI 1.31-9.21). Individuals who expected to be able to work fulltime or part-time were more likely to find work than individuals who expected not to be able to work (HR=4.09, 95%CI 2.57-6.53 and HR=2.33, 95%CI 1.46-3.72 respectively). With regard to maintaining employment, similar results were found, i.e. living with parents or independently (HR=13.59, 95%CI 1.82-101.29 and HR=15.31, 95%CI 1.79-130.93 respectively) and expectation to be able to work fulltime or part-time (HR=3.03, 95%CI 1.61-5.72 and HR=1.82, 95%CI 1.01-3.29 respectively). In addition, men were more likely to find and maintain work than women (HR=1.72, 95%CI 1.13-2.64). However, motivation was not statistically significantly related to maintaining employment.

Cox regression analyses on complete cases using all potential predictors (Method Enter) yielded coefficients of the same relative magnitude and direction as compared to the MI Cox regression analyses with all potential predictors. The only exception was that gender was not related to maintaining employment in the complete case analysis (HR 0.97, 95%CI 0.49-1.89), where as it was positively related in the MI analysis and that the coefficients for living situation were not estimable in this complete case analysis.

**Table 2. Results multivariate survival analysis STATA for work outcome with a backwards regression procedure<sup>a</sup>**

Variables	Finding work (yes/no)				Sustainable employment (yes/no)			
	HR	CI 95% lower	CI 95% upper	P-value	HR	CI 95% lower	CI 95% upper	P-value
<b>Gender (male)</b>					1.72	1.13	2.64	0.012
<b>Living situation</b> (ref residential placement/ sheltered accommodation)								
- Living independently (with or without partner)	2.94	1.20	7.21	0.018	15.31	1.79	130.93	0.013
- Living with parents/ family/foster family	2.96	1.50	5.81	0.002	13.59	1.82	101.30	0.011
<b>Expectation regarding future work level</b> (ref not able to work)								
- fulltime in a regular job	4.09	2.57	6.53	0.000	3.03	1.61	5.72	0.001
- part-time in a regular job	2.33	1.46	3.72	0.000	1.82	1.01	3.29	0.048
<b>Motivation (high)</b>	3.47	1.31	9.21	0.013	5.32 <sup>b</sup>	0.78	36.47	0.089

<sup>a</sup> Because of the considerable number of missing values for the covariates, missing data for these variables were imputed.

<sup>b</sup> HR, CI and p-value were taken from the pre-final step in the backwards regression analysis, after which motivation was excluded from the model.

## DISCUSSION

The results from our study indicate that motivation, expectations regarding future work level, living situation and gender are predictors for work participation for young adults with mild ID. In our study personal factors exceeded social factors in importance when predicting work participation in this group. Moreover, we did not find substantial differences between predictors for finding work and maintaining employment.

Results showed no substantial differences between predictors for finding work and maintaining employment. Living situation and expectation regarding future work level were found to predict both work outcomes for young adults with mild ID. Motivation did not reach significance for maintaining employment, but was only removed from the model in the backwards regression analysis in the pre-final step. As can be seen from table 2, this happened despite the fact that the HR was higher than in the analysis for finding work. This is caused by the fact that statistical power was reduced in the analysis for maintaining employment due to the limited number of young adults with mild ID that maintained work for at least six consecutive months during the follow-up. This also lead to rather broad CI's for the predictors in these analysis, meaning that, although these factors were statistically related to the outcome, the magnitude of our estimates (HR's) should be interpreted with caution.

The only relevant difference in predictors between both outcomes was the fact that gender was included in the final model for maintaining employment, whereas it was no predictor in the analysis for finding work. The fact that we did not find substantial differences in prognostic factors between both outcomes might be due to the length of the follow-up of our study, which was relatively limited. It may well be that this period is too short for young adults in the transition from school to work to find sustainable employment. At baseline 70% of our sample were still in education and may not have been ready yet to enter the labour market. However, as the majority of the individuals still at school were 18 years of age at baseline (71.5%) and ID-individuals in the Netherlands often finish their education at age 18, the majority will have left school during the follow-up, but they may not have had the chance to stay in work for at least six months. Only a small group of our sample were 17 years of age and at school ( $n=71$ ). Another possible explanation may be that young adults in general are known to change jobs regularly (UWV, 2011). The work status of our group of young adults with mild ID is not an exception in short and unstable employment trajectories, but they may have had more difficulty in finding a new job when losing a previous one. Both scenarios may have led to the limited number of individuals finding sustainable employment in our study.

In reviews as well as qualitative studies, both personal and social factors have been regularly mentioned as factors associated with work outcome in this group (Dixon & Reddacliff, 2001; Eisenman, 2003; Foley et al., 2012; Timmons et al., 2011) and the importance of especially personal factors for work participation was confirmed in our study.

The personal factors expectation regarding future work level and motivation both predicted work participation for young adults with mild ID. Results showed that expectations concerning work outcomes of the young adults themselves were a strong predictor of the actual work outcomes. When young adults expected themselves to be able to work, fulltime or part-time, they were more likely to find and maintain work than those who did not expect themselves to be able to work, although the difference between part-time work and not being able to work was borderline significant for maintaining employment. Positive expectations may stimulate finding work, but once employed other, e.g. work-related, factors may influence the effect of expectations on maintaining employment.

In our study self-esteem did not predict work outcome. Individuals with mild ID are sometimes found to be unable to assess themselves accurately. Inaccurate self-assessments may produce unrealistic expectations of unfeasible outcomes (Wehmeyer & Bolding, 2001) and become counter-productive.

Motivation was only statistically significantly related to finding work, but close to significance for maintaining employment ( $0.05 < p < 0.10$ ), while the HR was higher for this latter outcome, indicating a stronger effect. In the

literature motivation has been described as an enabling factor to find work, but also to overcome negative previous work experiences (Foley *et al.*, 2012; Timmons *et al.*, 2011). Although the effects of motivation on the work outcomes were strong, the accompanying CI's for maintaining employment, but also for finding work were large. This can be explained by the fact that, the distribution of our motivation variable was highly skewed, with more than 90 per cent of all individuals being highly motivated.

The social factors, social support and attitude regarding work, of parents as well as the social environment, were not predictive of work participation in our study. This is in contrast with findings from other studies, although evidence from these studies is limited (Dixon & Reddacliff, 2001; Foley *et al.*, 2012; Kirsh *et al.*, 2009; Timmons *et al.*, 2011). Nevertheless, reviews concluded family involvement to be an essential component of the transition process from school to work of young adults with intellectual disabilities by assisting individuals to develop a worker role (Foley *et al.*, 2012; Kirsh *et al.*, 2009). Qualitative studies identified several ways in which families were supportive of the efforts of young adults with mild intellectual disabilities to find (sustainable) competitive employment: families offered moral support and verbal encouragement; families were role modelling employment to show that work was an expected role in adulthood and emphasised work-related goals; families motivated the young adult to stay in a job and to value work and families displayed a strong work ethic (Dixon & Reddacliff, 2001; Timmons *et al.*, 2011). However, in spite of the findings of these descriptive studies, when tested empirically in our cohort, the social support and attitude of the social environment of the young adult with ID did not predict work participation. A reason for the limited effect of social factors on work participation in our study may have been that the available support has not been effective for these young adults. The majority of parents had a low educational level (57.0%), compared to 35.7% in the general Dutch population. These low educated parents may not have had the ability to be a role model and the resources to effectively support their young adult to find and maintain work.

The living situation of young adults with mild ID was the only significant social factor in our final model. Compared to young adults with mild ID living in residential institutions, those living with parents or living independently were more likely to find and maintain work. This is in concordance with the literature (Dusseljee *et al.*, 2011). However, although living situation is an important factor in the social environment of the young adult with mild ID, in this case living situation may also be interpreted as a proxy for severity of the disability. Individuals who were in residential placements probably had more severe disabilities, as was found in previous studies (Tossebro, 1995; Wehmeyer & Bolding, 2001). They may need more support in daily living activities, which also influences their employment opportunities. According to the Dutch Social Security Institute in the

Netherlands 65% of individuals in residential placement do not have an ability to participate in any kind of work, paid or unpaid, and 13% are involved in day centre activities, which may be work related but is unpaid (UWV, 2008).

In our study, we only included individuals with mild ID. This group represents a growing number of disability claimants in the Netherlands. In 2006 26% of young adults applying for a disability benefit had mild ID, in 2010 this percentage had risen to 29%. However, these young adults do have abilities to work and it is important to know which factors do influence work outcome for this group, to be able to support them to find and maintain employment. We did not include individuals with moderate or severe ID. Most of them did not have the ability to work according to the insurance physician. However, 7.5% of the individuals with moderate or severe ID in our cohort (n=147) did find work. This percentage is considerably lower than the percentage found in young adults with mild ID finding work (40.2%).

### **Strengths and limitations**

The strengths of this study are the size of our sample and the use of register data for work outcome, measured quarterly, allowing assessment of work outcome during the follow-up for the complete sample. However, some limitations must be taken into account as well. The personal and social factors included in the study were self-reported by the young adults with mild ID. They may have difficulty to make a realistic estimation of their capabilities and limitations. It may be difficult for this group to fill out a questionnaire requiring reflection on their own abilities, self-esteem, motivation and so on. Moreover, it is not clear whether the young adults with mild ID adequately understood the questions. Independent functioning is often felt as an important asset by this group and they may not have asked for assistance filling in the questionnaire when this was needed. This most probably will have led to underestimations of the relations under investigation. However, as we did find self-report variables predicting outcome, the respondents will have had some idea regarding the meaning of the questions. Work outcome was measured quarterly, so we may not have captured work performed in the months in between. Individuals may have found work, but not maintained it until the following measurement. With regard to maintaining employment, individuals may have found work, lost their job, but found new work before the following measurement. In this case sustainability is suggested, but in reality transitions may have taken place. However, it seems reasonable that the vast majority of individuals did not find more than two subsequent jobs in six months, so misclassification was presumably small.

## **Conclusion**

Personal and, to a lesser degree, social factors are valuable in predicting work participation. Motivation, expectations regarding future work level, living situation and gender all predicted work participation for young adults with mild intellectual disabilities. Results showed no substantial differences between predictors for finding and maintaining employment. As this study is the first prognostic study to our knowledge to assess the predictive value of personal and social factors related to work outcome in this group, further research is needed to establish the predictive value of the factors found. As personal factors were especially influential in predicting work outcome, motivation and expectations may be suitable factors to include in interventions designed to support young adults with mild ID to find and maintain work. Also further research is needed to assess whether expectations of individuals with mild ID are realistic or rather a self-fulfilling prophecy and whether these expectations can be influenced to foster positive work outcomes for these individuals. Moreover, further studies would need to consider the types of work performed, the work position, and the attitudes of employers and colleagues of individuals with ID as a fit between the individual, the job and the work environment is essential for successful sustainable work participation.

This study portrays the position of individuals with mild intellectual disabilities in the labour market, and the benefits they hope to gain by being employed. The study focuses on the issue of sustainable employment, which is a common problem for individuals with ID as they struggle to maintain employment once they found a job. To ensure a good job match, it is important that parents, school teachers and transition counselors encourage young adults with ID to express their desires and affinities regarding employment. When these are taken into account in job searching, their feelings of competence and autonomy may increase and have a positive influence on personal attributes, like motivation and expectations. As expectations are an important predictor for both work outcomes, realistic expectations are imperative for being successful in finding as well as maintaining employment. Parents, school teachers and transition counselors should help young adults with ID to develop these realistic expectations for future employment. Once working, young adults with ID are in a vulnerable position on the labour market and it is important for them to receive specific and continuing support on the job, e.g. from their employer or a colleague, to be able to maintain employment.

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# CHAPTER 8

## General discussion





## MAIN FINDINGS

The overall objective of this thesis was to gain insight into the personal and social environmental factors predicting work participation, finding as well as maintaining employment, among young adults with disabilities applying for a disability benefit. This objective has been translated in two main research questions:

1. Which personal and social environmental factors predict work participation of young adults with disabilities applying for a disability benefit?
2. Do personal and social environmental predictors differ for disease-specific subgroups?

The main findings regarding these two research questions will be discussed. Furthermore, the strengths and limitations of the research will be discussed. Finally, implications for policy and practice and directions for further research will be provided.

### Personal and social environmental predictors for work participation

In our studies we found personal (demographic and psychological) as well as social environmental factors predicting work participation: finding and maintaining employment. Age and gender were found as demographic personal predictors for finding as well as maintaining employment. Relatively older and male young adults were more likely to find and maintain employment than younger and female young adults with disabilities. Positive expectations regarding future work (fulltime and part-time) and higher motivation were the psychological personal factors found to predict finding employment. Living independently or with parents or family was found to be an important social predictor for finding as well as maintaining employment. A positive attitude from parents regarding employment was found to predict finding work, while a positive attitude of the social environment (e.g. friends) regarding employment was found to predict finding as well as maintaining employment. High perceived support from parents was inversely related to finding employment and not related to maintaining employment. Predictors for finding employment partly differed from predictors for maintaining employment. Psychological personal factors were more influential in finding employment, while social environmental factors influenced finding as well as maintaining employment.

Motivation and expectations regarding future employment were the only two psychological personal factors found to predict work outcome (chapter 6 & 7). Young adults with higher motivation had a higher chance of finding employment. The influence of motivation on employment has been well established in literature regarding young adults with disabilities (*Auerbach & Richardson, 2005; Foley et al., 2012; Linden et al., 2010; Rose et al., 2005; Stahl et al., 2011; Suzuki et al., 2008; Timmons et al., 2011*). Also, lack of motivation has been found to be an internal barrier to employment for these young adults (*Winn & Hay, 2009*).

Positive expectations regarding future employment of young people with disabilities influenced the chance of finding employment (chapter 6 & 7). However, when examining the predictive value of expectations from different perspectives (young adult with disability, their parents and their school teacher), the expectation of the school teacher was the only perspective that significantly predicted entering competitive employment, with a small complementary effect of the prediction of parents and a very small additional effect of the expectation of the young adult (see chapter 4). Of these young adults, more than half expected to be able to work in competitive employment. In general, their parents shared this expectation. The teachers were less optimistic. Expectations of both school teachers and parents are valuable in predicting employment outcome and in setting realistic expectations for the young adult in the transition to employment. Teachers substantially contribute to the educational preparation of the young adult for the workforce and play a critical role in their subsequent transition to employment (*Eisenman, 2007; Kim & Dymond, 2010; Laragy, 2004; Oeseburg et al., 2010*). Family expectations for employment have been linked to motivation to find employment and achievement of young adults with disabilities (*Doren et al., 2012; Newman, 2005*). Moreover, the majority of young adults with disabilities perceive that their parents want them to work (*Blomquist, 2006; Lindstrom et al., 2011; Newman, 2005*).

In spite of these positive expectations and motivations, in the 18 months following claim assessment only 39% of these young adults did actually enter competitive employment. This rather low percentage of young adults entering competitive employment may be partly an effect of legislation (e.g. the Invalidity Insurance Act for Young Disabled Persons) and social policy, vocational programs that are available to this population, availability of jobs and readiness of the employers to integrate this population into the work force. Another reason may be that part of the young adults is still in education, but we expect this to be a very small percentage (see Methodological considerations). Most young adults from special needs education in the Netherlands finish their education at 18 years of age.

The social context has been found to be related to work outcome. Besides living situation, positive attitudes from parents and social environment regarding employment were found to predict work participation (see chapter 6). On the other hand, according to literature, individuals with cognitive impairments are sometimes discouraged by family and friends to work (*Lindsay, 2011*). Parents of the young adult with disability are especially influential in the transition from school to work. They have an important role in holding back or stimulating participation in work. High perceived support from parents was inversely related to finding employment. A possible explanation is that parents are protective, fearing possible negative health consequences of work for their young adults. They may also be aware of possible discrimination in the workplace and wanting to protect their child

against this experience (*Lindsay, 2011*). Support of family during the transition process from school to work is essential to reach a satisfactory outcome (*Galambos et al., 2006; Heslop & Abbott, 2007; Howlin et al., 2004; Szatmari et al., 1989; Winn & Hay, 2009*). In literature it has been confirmed that friends and neighbours can also be a role model for individuals with DD in showing employment as a valued aspect of adulthood (*Jennes-Coussens et al., 2006*).

We found that perceived support from parents was not related to maintaining employment. Once working, the social network of working individuals with disabilities may broaden (*Ridley & Hunter, 2006*). The support of supervisors and colleagues in their immediate working environment has been found to be very important for these young adults to alleviate the stress and insecurity resulting from these new experiences and challenges (*Storey, 2003; Vorhies et al., 2012*). When active in the workplace, they encounter many new experiences and challenges which may overwhelm them. Because of their limited abilities to cope with these (new) challenges and their often limited social and communicative skills, these young adults could feel like quitting. Without the pro-active support of their supervisors and colleagues, they might not be able to maintain their job.

Our results could not confirm that self-esteem and self-knowledge are important psychological personal predictors on work participation, as found in other studies (*Eisenman, 2003; Lindsay, 2011; Lindstrom et al., 2011; Shier et al., 2009*). A possible reason might be, that personal factors like self-esteem and self-knowledge are abstract concepts. Young adults with disabilities, especially those with cognitive or mental disabilities, often have difficulty to self-report these measures that require self-insight (see also Methodological considerations).

### **Predictors for work participation for disease-specific subgroups**

In this thesis predictors for finding and maintaining employment of young adults with developmental disorders as well as young adults with intellectual disabilities have been examined separately (chapters 5, 6 and 7). We found differences in social environmental predictors between the two disability groups. Both groups shared the same personal predictors.

Gender, living situation, motivation and expectations regarding future employment predicted work outcome for individuals with intellectual disabilities (ID), as well as those with developmental disabilities (DD). The support and attitude of parents predicted work outcome for individuals with DD, but not for those with ID. One possible reason for the lack of significance of this predictor in individuals with ID is that living situation is a strong predictor for their work outcome and 77% of them still lived with their (foster) parents or family. There is a strong link between living at home and the support individuals receive from their parents.

The attitude of the social environment regarding employment predicted work outcome only in individuals with DD. Despite the social impairments

often mentioned in connection with DD, individuals with DD are stimulated to find employment by a positive attitude of their social environment. These individuals may look for a sense of belonging and therefore be more attentive to the attitudes of their social environment regarding employment. Individuals with ID often are more dependent on their family and have limited social contacts outside of the family, as suggested by other studies (Dixon & Reddacliff, 2001; Foley et al., 2012; Timmons et al., 2011).

In our cohort the majority of young adults had a mental health disorder, 43% of the young adults had a primary diagnosis of intellectual disability, 28% a developmental disorder and 17% another psychiatric disorder (Holwerda et al., 2012a). Therefore, in our articles (chapter 4-7) we focused on young adults with this type of disabilities. In many European countries a majority of young people with disabilities are diagnosed with mental health disorders and mental health and psychosocial impairments are increasing, especially amongst young people (Eurofound, 2012). Research suggests that people with mental disabilities or intellectual disabilities are more disadvantaged in education, employment and independence than other disability groups (WHO & World Bank, 2011).

Whether differences exist in predictors for work participation between individuals with somatic disorders compared to mental health disorders has not been studied in this thesis. In our cohort study only 12.4% (N= 218) of the young adults had a somatic disease as primary diagnosis, of which musculoskeletal disorders and nervous system diseases were most common. The total group of young adults with somatic diseases in our cohort was too small to study predictors for work participation and to compare the results with the mental disability groups.

### **METHODOLOGICAL CONSIDERATIONS**

Strengths of the “Young Disabled at Work” cohort-study are the size of our sample (n=3455), allowing assessment per diagnosis group, and the longitudinal design for three of our studies. The target group is a heterogeneous group with different types of health conditions and different abilities and limitations which can influence the relevance and strength of association between predictors and work outcome. Therefore, we performed separate analyses for several disability groups. The use of register data for work outcome, measured quarterly, allowed accurate assessment of work outcome during the follow-up for the complete sample. Demographic data as well as data regarding diagnosis, disability benefit and work outcome were available for all participants. For our cohort, we included all applicants for a disability benefit in three Northern provinces of the Netherlands during 2009, securing the representativeness of the sample for the population of young disability claimants in the Netherlands.

Furthermore, we collected data from different perspectives. The young disabled adults themselves filled out a questionnaire regarding their psychosocial

characteristics, their parents/caregivers did if they were still living at home and their school supervisor did if they were attending special needs education. Furthermore, the insurance physician and labour expert of the social security institute filled in questionnaires regarding disability, limitations and work ability. Our study is the first to assess the extent to which insurance physicians take into account comorbidity, secondary conditions and problems in social context of young adults applying for a disability benefit, in addition to primary and secondary diagnosis.

Some limitations must be taken into account as well. The questionnaires filled out by the young adults with disabilities, their parents and school supervisors consisted of questions that were partly adapted from existing questionnaires (*De Vos, 2008; GGD Flevoland, 2003; RIVM, 2005; Statistics Netherlands, 2005*) and partly self-constructed. It was inappropriate to utilize existing questionnaires for this group, because of the limited cognitive abilities of the majority of the participants.

A potential limitation is the amount of missing data resulting in analyses of 76.8% of the available cases. This may have led to a slightly different distribution of the primary diagnosis in our cohort. Compared with the data of the Social Security Institute, the prevalence of mild intellectual disability in our cohort is slightly higher than reported by the SSI (35% vs 29%) and the prevalence of other psychiatric disorders in our cohort is somewhat lower than reported by the SSI (17% vs 21%) (*UWV, 2011*). However, it is not expected that a slightly different distribution of diagnosis will have significantly altered our findings regarding the associations with workability.

The limited availability of the expectations of teachers and missings in the expectations of young adults and parents made that of 47% of the respondents complete data from all perspectives were available and could be included in the analyses. Non-response analyses showed no statistically significant differences between the respondents with complete and incomplete data with regard to gender, age and diagnosis. As only young adults applying for a disability benefit were included in the cohort-study, it may have caused selection bias. However, the majority of young adults in special needs education in the Netherlands apply for a disability benefit, so no large differences between the population from special needs education and our sample are expected. Besides, we cannot rule out the possibility that there might have been differences in the characteristics of parents and school teachers of responders and non-responders; more concerned and involved parents and school teachers filling out the questionnaire may have biased the results. It is unknown whether the predictions of these parents and teachers are more or less accurate than those from less concerned parents and teachers. The missing values could have led to less precise estimates of the parameters of interest.

At baseline most of the respondents were still at school. It is unknown whether individuals that were still in education at the start of the study, finished their

education within the 18 months of follow-up and therefore some may not have been able to participate in work during the follow-up because of this. However, because of the generally low educational attainment of individuals with disabilities and because most students in the Dutch special needs educational system leave school at 18 years of age, we expect most students to have left school during the follow-up and had the opportunity to enter competitive employment.

Work outcome was measured quarterly, so we could not capture paid work performed in the months in between, i.e. individuals who found employment, but did not maintain it until the following measurement were not registered as finding employment. On the other hand, in the case of individuals who found employment, lost their job, but found new paid work before the following measurement, sustainability is suggested, where in reality transitions took place. However, it is reasonable to presume that the vast majority of individuals did not find more than two subsequent jobs in six months, so misclassification was presumably small.

The personal and social factors included in our studies regarding predictors for work participation of young adults with DD and with mild ID were self-reported by the young adult. They often have difficulties to make a realistic estimation of their capabilities and limitations and to adequately reflect on their own abilities, self-esteem, motivation and so on. Moreover, it is not clear whether these individuals adequately understood the questions. Independent functioning is often felt as an important asset by this group and they may not have asked for assistance filling in the questionnaire when this was needed. Probably this has led to underestimations of the associations under investigation between the potential predictors and work outcome.

### **GENERALIZABILITY**

Our sample represents all young adults applying for a disability benefit in the Northern Netherlands and was representative for the national influx of young adults applying for disability benefits in 2009 and 2010 with regard to gender, age, living situation and disability groups, except for intellectual disabilities (45% versus 38%) and somatic diseases (10% versus 13%). The characteristics of the working young adults in our cohort were also nationally representative with regard to gender, age, diagnosis, attitude and type of work (*UWV, 2011*). In comparison with the new national influx in 2012, our cohort was similar with regard to diagnoses except for somatic diseases (10% versus 13%), but a bit older (80% versus 87% younger than 24 years) (*www.uwv.nl*).

As we only included those young adults applying for a disability benefit, it is not possible to generalize our results with regard to young adults with disabilities not applying for disability benefits. Not all young adults with disabilities apply for a disability benefit. Individuals with an adequate level of independent functioning may not deem it necessary to apply for a disability benefit. We assume this applies mainly to individuals with somatic diseases,

as only a small percentage of them was included in our cohort (12% versus 36 % in the general population of 15-25 years). In the Netherlands a large percentage of young adults with intellectual and developmental disabilities attend special needs education. These individuals are often encouraged by their school teachers to apply for a disability benefit as a safety net, even when they do have the ability to work, but need support in the work place. So we estimate our results can be generalized for individuals with intellectual and developmental disorders, because presumably almost all of them are included in our cohort.

## **IMPLICATIONS AND RECOMMENDATIONS**

### **Young adults with disabilities in a societal context**

In the past decade the number of young people with disabilities has increased considerably. This is partly the result of medical advances preserving life with more survivors with chronic and systemic diseases as a result (*Blomquist, 2006; WHO, 2010*). Another reason is the increasing complexity of our society, creating a larger percentage of individuals not able to cope with the demands placed on them by our educational and societal systems. On the one hand, limited intellectual skills are more frequently felt and labelled as a disability, because of the decreasing availability of suitable jobs and duties for people with limited intellectual skills. On the other hand, in today's highly structured educational system, there is less room for unfocused behaviour, potentially leading to a faster labelling of behaviour as i.e. attention disorder. A growing number of children with disabilities leads to an increasing need for special needs education. In the Netherlands, secondary special needs education has increased from 15.000 students in 2000 to 34.000 students in 2010, on a total of 940.000 students in secondary education in 2010 (*www.cbs.nl*). Children with special education needs are more likely to apply for a disability benefit when growing up. The number of individuals applying for a disability benefit in the Netherlands has increased from 7.700 in 2002 to 17,800 in 2010 (*UWV, 2012*). The majority of young people with disabilities receiving a disability benefit in the Netherlands has a mental disability, as elaborated above. In addition to their primary disability, 54% of these young adults had at least one other chronic condition, with developmental disorders and psychiatric disorders being most common (*Holwerda, 2012b*).

As disability is complex, dynamic and multidimensional, the "medical model" for framing disability does no longer suffice. Instead a "biopsychosocial model" has been developed in recent years, in which people are viewed as being disabled by society rather than by their impairments (*WHO & World Bank, 2011*). Without disregarding the limitations young adults with disabilities experience, in the biopsychosocial model of disability, disability is seen as the result of the interaction between an individual's impairment and the barriers existing in society. In this model of disability, systemic barriers, negative attitudes and exclusion by society (purposely or inadvertently) define who is disabled and who is not in a particular society. Although it

recognizes the physical, sensory, intellectual, or psychological variations often resulting in functional limitations or impairments, these will only lead to disability if society fails to include these individuals (*www.eurade.eu*). That is why the United Nations endorsed a Convention on the Rights of Persons with Disabilities (see box 1).

*Box 1: Perspective United Nations and European Union*

The United Nations Convention on the Rights of Persons with Disabilities (2006) states that *“the right of persons with disabilities to work, on an equal basis with others should be recognized; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to people with disabilities.”*

([www.un.org/disabilities/convention/conventionfull.shtml](http://www.un.org/disabilities/convention/conventionfull.shtml)).

The European Union has endorsed this UN-convention and formulated an “European Pact on the Equal Rights of Persons with Disabilities” In which they stress that for this group to have equal access to employment, tailor-made services in education, vocational training and placement services and assistance in finding employment and support on the job to be able to maintain employment are necessary taking into account individual strengths and needs (EDF, 2009).

Inclusion of young adults with disabilities in employment is desirable, from a personal as well as from a societal perspective. Evidence suggests that employment is favourable for health and well-being. For a society to be inclusive, the focus should be on abilities rather than on disabilities: individuals with a disability need to be assessed according to their abilities. In the Netherlands, recently initiatives have been taken to incorporate this idea in national and local policies. However, according to the biopsychosocial model described above, young adults cannot bear the sole responsibility for their participation. Society as a whole has a responsibility to enable and facilitate individuals with abilities as well as limitations to find and maintain employment. Moreover, because of their vulnerable labour market position, adequate support from formal sources, like school supervisors, transition counsellors and employers, as well as informal sources, like parents, friends and neighbours, is needed.

### **Significant others**

Significant others, like parents and school teachers, should be involved in the decision making process in the transition from school to work. The combination of these two perspectives gives a realistic outlook on the ability of the young adult regarding competitive employment. Co-operation of school teachers and parents in setting realistic expectations for the young adult is necessary to ensure the best possible employment outcomes for the young adult. As young adults with disabilities are especially vulnerable, parents

should be enabled to be their advocates in securing vocational training, placement and employment. School teachers should allow parents to be involved in this process. If parents are vulnerable themselves as well, school teachers should be able to take this role of advocacy for the young adult with disability and support the young adult and their parents in decision making regarding vocational training and future employment. Our results showed that parents and school teachers are well able to predict future work ability of the young adult with disability. This is valuable information for the Social Security Institute when assessing the ability to work of the young adult. Therefore, the insurance physicians and labour experts of the Social Security Institute should take the opinion of parents and school teachers into account, when deciding regarding disability benefit and resources for support to find and maintain employment.

### **Work participation: matching work abilities and work demands**

Our results showed that many young adults with disabilities do have the ability to work. However, there still exists a substantial discrepancy between the abilities of young adults with disabilities and their actual work participation. Research shows that the employment rates of young adults with disabilities are considerably lower than those in the general population (*Pascall & Hendey, 2004; Randolph, 2004; UWV, 2008; 2011*). One reason is that it takes time to support young adults with disabilities to find employment, e.g. because they need additional training or re-integration services (*UWV, 2011*). The economic situation is also an important factor influencing the uptake of young adults in the labour market. The unemployment rate of young adults in general (15-25 years) in the Netherlands has risen from 9.3% in 2008 to 15,5% in 2013 (*www.cbs.nl*) and in Europe the unemployment rate of young adults has risen from 15% in 2008 to 22,6% in 2012 (*European Commission, 2012*). For vulnerable young adults, like those with disabilities, unemployment percentages exceed those of their peers without disability, indicating that European labour markets are still far from inclusive. In this tight labour market for young adults in general, young adults with disabilities need protection and support to prevent their labour market exclusion.

We found that most of the working young adults in our cohort worked in retail, for temporary job agencies, in agriculture/food industry and health care. This is confirmed by the literature, indicating that young adults with disabilities are mainly employed in low status, unskilled occupations that are poorly paid (*Carroll & Dockrell, 2012; Howlin et al., 2004; Lindsay, 2011; Taylor & Seltzer, 2011; Verdonschot et al., 2009*). Other research has shown that 44% of workers with disabilities are in contingent or part-time employment, providing lower pay and fewer benefits, compared with 22% of those without disabilities (*WHO & World Bank, 2011*). These poor employment perspectives hinder young adults with disabilities to become fully independent and self-sufficient. Therefore, employers and organisations need to facilitate the

professional development of these young adults and invest in schooling and training on the job, so individuals with the ability and the desire to advance their employment career are accommodated. It is important that individuals with disabilities are not made solely responsible for their work participation. Individuals cannot be pushed into jobs by using economic incentives (EDF, 2009), as is suggested by the Dutch government by launching their newest legislation proposal regarding young adults with disabilities. Young adults with disabilities can only work in competitive employment when employers, companies and organizations are willing to employ and support them. Concerted action from governments, school and employers is needed to support young adults with disabilities to find and maintain employment. The inclusion of young adults with disabilities requires a cultural change and employers, employees and government need to act in shared responsibility.

### **Employer and social policy**

To accomplish labour market inclusion, the Dutch government plans to enforce activating regulations to stimulate work participation of young adults with disabilities (SZW, 2013). In the Netherlands this year (April 2013) a new social agreement has been signed between the government and the social partners (trade unions and employers organizations) with the objective to give as many people as possible a fair chance to find competitive employment and to gain financial independence. A structural reform is necessary because of the unfavourable economic circumstances in the Netherlands, as well as in other countries around the world. Moreover, the continuing changes in the economy and the accompanying technological development require adjustments in the labour market. Therefore, signing parties have agreed to create opportunities and support for individuals with disabilities, who have a hard time finding employment without (financial) support from companies, municipalities and social partners. To realize this objective, municipalities and social partners have agreed to establish regional employment offices, as intermediaries between individuals with disability and employers. Employment offices need to ensure job placements and supervision for individuals with disabilities. If necessary, employers can claim supplementary wage allowances for employees who are less productive because of their disability. Employers have warranted to create additional jobs for young adults with disabilities, from 2.500 in 2014 to a maximum of 100.000 additional jobs in 2026. This agreement will be monitored by the government and legislation regarding compulsory quota will be implemented if insufficient jobs have been created by 2016 (SZW, 2013). Every year around 10.000 new young adults with disabilities will join their peers in searching the labour market for employment. Additional jobs created by the agreement mentioned above, will not suffice to employ all the young adults with disabilities looking for work. Therefore, employers, municipalities and the social security institute will need to cooperate to ensure more em-

ployment options for young adults with disabilities. One way of creating suitable jobs for young adults with disabilities is changing the perspective to task-oriented jobs, instead of position-oriented jobs, so-called job-carving. By looking at tasks rather than positions, jobs can be accommodated to the abilities of young adults with disabilities. Young adults can also fill in community jobs, that otherwise not get done. These jobs are often valuable to society and appreciated by the people living in a community and may also enhance self-esteem and well-being of the young adult involved. Supported employment is another option to employ young adults with disabilities, that has been extensively studied in the literature, with positive results.

### ***FUTURE RESEARCH***

Disability is a complex and dynamic concept and young adults who experience disability need our continuing effort to facilitate their work participation. Future research should focus on the role of significant others, like family and friends, in the transition from school to work. It is unclear how significant others can be facilitated to advocate for the right to work of young adults with disabilities and to stimulate their work participation according to their ability. Further research is needed to discern how young adults with disabilities need to be supported to be able to find and maintain employment. As only 20% of young adults with disabilities are able to maintain employment, supervisors and co-workers need to be involved in research investigating the work and workplace-related factors predicting maintaining employment as well as the effect of support on the job in maintaining employment. Effective support strategies to ensure increased work participation for young adults with disabilities are unknown. Further research is also necessary to confirm the predictors found in our studies in larger samples and with longer follow-up periods. Moreover, future research should further explore whether possible modifiable personal factors, like self-esteem and self-knowledge, influence work participation of young adults with disabilities. For the predicting factors, like motivation and expectations, interventions can be developed to enhance the impact of facilitating factors and reduce the effect of negative influences on work participation of young adults with disabilities.

Next to our cohort of young adults applying for a disability benefit, other groups of young adults with disabilities should also be examined for predictors of work participation, e.g. young adults with disabilities leaving vocational training schools or secondary special needs education schools.

Considering the lack of prospective longitudinal studies regarding factors predicting work outcome for young disabled adults, our studies regarding predictors for work participation in young adults with developmental disorders and those with intellectual disabilities contribute to the knowledge base on which future studies can be built.

### **GENERAL CONCLUSION**

The majority of young adults with disabilities are diagnosed with a mental disorder, like intellectual disability, other developmental disorders or psychiatric disorders. Moreover, young adults with disabilities often experience multi-morbidity, with interacting conditions to intensify the limitations and influence work ability. Despite their limitations, the majority of those young adults has abilities to work, although most of them need support to find and maintain (competitive) employment. Although they do have abilities to work, employment rates lag far behind those of the general population. Next to the medical condition(s) of these young adults, personal and social factors influence work participation. Significant others, like parents and school teachers, play an important role in finding employment by these young adults. Once they start to participate in work, employers and colleagues should take on this role and need to be facilitated and stimulated to support young adults with disabilities to maintain employment. These factors need to be taken into account when developing interventions for young adults with disabilities to support them to find and maintain employment. Finally, employers, municipalities and national governments need to be involved in providing suitable jobs for young adults with disabilities and policies need to be adapted to include young adults with disabilities as full-fledged citizens.

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# SUMMARY





In the past decade the number of young people with disabilities has increased considerably. These young adults experience physical, mental and/or developmental disabilities and many experience limitations in their personal functioning resulting in limited participation in society. In general, young adults with disabilities are much less likely to be employed than their non-disabled peers. This limited work participation of the individual can be influenced by disease or disorder, but also by personal factors (e.g. age, gender, self-esteem and motivation) and by environmental factors (e.g. the social context). Knowledge regarding opportunities for young adults with disabilities to participate in work and factors that influence the realization of these opportunities in practice is hardly available (**Chapter 1**). Therefore, the objective of this thesis is to gain insight into the personal and social environmental factors predicting work participation, finding as well as maintaining employment, among young adults with disabilities applying for a disability benefit. This overall aim has been translated into two main research questions:

1. Which personal and social environmental factors predict work participation of young adults with disabilities applying for a disability benefit?
2. Do personal and social environmental predictors differ for disease-specific subgroups?

**Chapter 2** describes the design and methods of the “Young Disabled at Work” cohort-study, a longitudinal prospective study following young adults applying for a disability benefit for a two-year follow-up period. Data were collected through questionnaires. To get a realistic picture of the young adult with disability, we asked themselves, their parent(s), and their school teacher and insurance physician to fill out a questionnaire to provide information. The questionnaire consisted of items regarding demographics, disease-related, personal and social environmental factors in accordance with the International Classification of Functioning, Disability and Health (ICF). Our outcome measure was defined as finding and maintaining employment in which only paid work for any number of hours was included.

In **chapter 3** a study is presented examining the factors associated with work-ability level as assessed by the insurance physician of the social security institute among young adults with disabilities applying for disability benefits. Of the participants, 57.2% were male and 42.8% female, with a mean age of 19.6 years (SD 2.6). Of them 42.5% had a primary diagnosis of intellectual disability, 28.2% had a developmental disorder, 16.9% had another psychiatric disorder, and 12.4% had somatic diseases. More than half of the individuals had one or more co-morbid condition(s). According to the insurance physician (IP), 84.2 percent (n=1478) had abilities to work. In this study we found that primary diagnosis, comorbidity and subclinical mental complaints were associated with IP-assessed work ability. Persons with mental health conditions as primary diagnosis were less likely to reach a higher work ability

than persons with somatic diseases. Young adults with two or more comorbid conditions and those with psychiatric or developmental comorbidity were less likely to reach a higher work ability level than persons without comorbidity. Young adults with subclinical mental complaints were half as likely to reach a higher IP-assessed work ability than young adults without this condition.

In **chapter 4** the expectations in the transition from school to work of young adults with mental disabilities from special needs education, their parents and their school teachers regarding future ability to work in competitive employment are described. Furthermore the ability of these young adults, their parents and their school supervisors to predict future work status has been addressed and the most predictive perspective of work outcome after leaving school was identified.

More than half of the young adults and parents and 37% of the teachers expected the young adult to be able to work in competitive employment, compared to 39% that actually entered competitive employment in the 18 months following claim assessment. Young adults with mental disabilities, their parents and their school teachers were moderately able to predict future work when expecting the young adult to be able to work in competitive employment. The expectation of the school teacher was the only perspective that significantly predicted entering competitive employment, with a small complementary effect of the prediction of parents and a very small additional effect of the expectation of the young adult. We concluded that expectations of school teachers and parents are valuable in predicting employment outcome. Co-operation of school teachers and parents in setting realistic expectations for the young adult is therefore necessary to ensure the best possible employment outcomes for them.

In **chapter 5** a systematic review of the literature is presented regarding facilitating or hindering predictors for work participation in individuals with autism spectrum disorders (ASD). Seventeen factors, categorized as disease-related factors, personal factors or external factors, were found to be related to work outcome. Limited cognitive ability was the only significant predictor consistently found. Functional independence and institutionalization were both reported by one study to be significantly related to work outcome. Inconsistent findings or non-significant findings were reported for the other fourteen factors. This review points to an important gap in the literature regarding predictors of work outcomes in individuals with ASD. There is a need for more high quality cohort studies focussing on work participation as the main outcome among people with autism spectrum disorders. Moreover, the findings of this review emphasize the need for adequate intervention and services, geared to the needs of the individual with ASD, that help them to adjust to the psychosocial demands in society.

**Chapter 6** presents the factors predicting work participation, finding work as well as maintaining employment, of young adults with autism spectrum disorders (ASD) and attention deficit disorders (ADD).

Both personal and social factors were found to be important in predicting work outcome, and predictors for finding work differed substantially from predictors for maintaining employment. Living situation and motivation appeared to be only influential for individuals with ASD, while gender only influenced work outcome for individuals with ADD. Besides socio-demographic characteristics (age, gender, living situation) we found that expectations regarding future work level by the DD-individuals themselves is an important predictor for finding work. Therefore, it is important for professionals to take the expectations of individuals with DD into account when supporting these individuals to find work. As the social context of individuals with DD seem to play a major role in finding and maintaining work, they need to be taken into account as well by professionals working with individuals with DD in their transition to find work.

In **chapter 7** the predictors of work participation of young adults with mild intellectual disabilities (ID) are described. Personal and, to a lesser degree, social factors were found to be valuable in predicting work participation. Motivation, expectations regarding future work level, living situation and gender all predicted work participation for young adults with mild intellectual disabilities. Results showed no substantial differences between predictors for finding and maintaining employment. Especially personal factors are influential in predicting work outcome and may be suitable factors to include in interventions. As expectations are an important predictor for both work outcomes, realistic expectations are imperative for being successful in finding as well as maintaining employment. Therefore, it is important for parents, school teachers and transition counselors to help young adults with ID to develop these realistic expectations for future employment.

**Chapter 8** provides an overview of the main findings of this thesis as well as a discussion regarding its strengths, limitations and also its implications for policies and practices and directions for further research. Inclusion of young adults with disabilities in employment is desirable, from a personal as well as from a societal perspective. For a society to be inclusive, the focus should be on abilities rather than on disabilities. This does not mean that young adults with disabilities should bear the sole responsibility for their participation. Society as a whole has a responsibility to enable and facilitate individuals to find and maintain employment. Young adults with disabilities can only work in competitive employment when employers, companies and organizations are willing to employ and support them. Moreover, because of their vulnerable labour market position, adequate support from formal sources, like school supervisors, transition counsellors and employers, as well as informal sources, like parents, friends and neighbours, is needed.



# SAMENVATTING





Een toenemend aantal jongeren ondervindt als gevolg van ziekte of aandoening beperkingen in het maatschappelijk participeren. De meeste van hen ervaren mentale beperkingen, zoals verstandelijke beperkingen, psychische en/of ontwikkelingsstoornissen. Deze jongeren hebben veel minder kans om deel te nemen aan het arbeidsproces dan hun gezonde leeftijdsgenoten. Deze beperkte arbeidsdeelname wordt niet alleen veroorzaakt door de gevolgen van de ziekte of aandoening, maar wordt ook beïnvloed door persoonlijke factoren (zoals leeftijd, geslacht, zelfbeeld en motivatie) en omgevingsfactoren (zoals de sociale context). Jongeren met een beperking, die niet kunnen werken of beperkte arbeidsmogelijkheden hebben, krijgen een Wajong-uitkering (Wet arbeidsongeschiktheidsvoorziening jonggehandicapten). Het UWV voert deze wet uit, verzekeringsartsen en arbeidsdeskundigen beoordelen het arbeidsvermogen en maken een participatieplan. In de afgelopen jaren is het aantal Wajong-uitkeringen fors toegenomen. Voor het verzekeringsgeneeskundig en arbeidskundig handelen in de praktijk is het van belang om inzicht te hebben in de bevorderende en belemmerende factoren die een rol spelen bij de arbeidsparticipatie van deze jongeren. Tot op heden ontbreekt het echter aan kennis over zowel de participatiemogelijkheden van jongeren met een beperking in werk als de mate waarin bovengenoemde factoren het benutten van deze mogelijkheden in de praktijk beïnvloeden (**Hoofdstuk 1**).

Het doel van dit proefschrift is om inzicht te verkrijgen in de persoonlijke en sociale omgevingsfactoren die arbeidsparticipatie, zowel het vinden als behouden van werk, van jongeren met een beperking die een Wajong-uitkering aanvragen, beïnvloeden. Dit doel is vertaald in twee onderzoeksvragen:

1. Welke persoonlijke en sociale omgevingsfactoren voorspellen arbeidsparticipatie van jongeren met een beperking die een Wajong-uitkering aanvragen?
2. Verschillen persoonlijke en sociale omgevingsfactoren die arbeidsparticipatie voorspellen voor ziekte-specifieke subgroepen?

In 2008 is gestart met de cohortstudie “Participatiemogelijkheden in werk van Wajonggerechtigden”. **Hoofdstuk 2** beschrijft het design, de opzet en methoden van deze cohortstudie, een longitudinale prospectieve studie van jongeren die in 2009 in regio Noord een Wajong-uitkering hebben aangevraagd, met een follow-up periode van twee jaar. De dataverzameling vond plaats doormiddel van vragenlijsten. Om een realistisch beeld van de doelgroep te verkrijgen, zijn met behulp van vragenlijstonderzoek zowel gegevens over de jongeren verzameld via henzelf, via de ouder/verzorger en de leerkracht/schoolbegeleider als via de verzekeringsarts van het UWV. De vragenlijst bestond uit vragen over demografische factoren, zoals leeftijd, geslacht en opleiding, ziekte-gerelateerde factoren en persoonlijke en sociale omgevingsfactoren, conform de Internationale Classificatie van Functioneren van de Wereldgezondheidsorganisatie (International Classification of Functioning, Disability and Health (ICF)).

De uitkomst werd gedefinieerd als het vinden en behouden van werk, waarbij alle loonvormende arbeid werd meegenomen en geen minimum aan het aantal uren werd gesteld.

Op het moment dat een Wajong-uitkering wordt aangevraagd worden de arbeidsmogelijkheden door het UWV in kaart gebracht. In **hoofdstuk 3** wordt beschreven welke factoren geassocieerd zijn met de arbeidsmogelijkheden van jongeren die een Wajong-uitkering aanvragen, zoals beoordeeld door de verzekeringsarts van het UWV. Van de deelnemers was 57,2% man en 42,8% vrouw met een gemiddelde leeftijd van 19,6 jaar (SD 2,6). Van hen had 42,5% een verstandelijke beperking als hoofddiagnose, 28,2% had een ontwikkelingsstoornis, 16,9% had een andere psychiatrische aandoening en 12,4% had een somatische aandoening. Meer dan de helft van de respondenten had één of meer neventdiagnose(s). Volgens de verzekeringsarts (VA) had 84,2% van de respondenten mogelijkheden om te werken. Uit deze studie bleek dat hoofddiagnose, co-morbiditeit en subklinische psychische klachten waren geassocieerd met de door de VA vastgestelde arbeidsmogelijkheden. Respondenten met een psychische aandoening als hoofddiagnose hadden gemiddeld een lager niveau van arbeidsmogelijkheden dan respondenten met een somatische aandoening. Jongeren met twee of meer neventdiagnoses en degenen met een psychiatrische aandoening of ontwikkelingsstoornis als neventdiagnose hadden gemiddeld ook een lager niveau van arbeidsmogelijkheden dan jongeren zonder neventdiagnoses. Jongeren met subklinische psychische klachten hadden twee keer zo vaak een lager niveau van arbeidsmogelijkheden dan jongeren zonder deze klachten.

In **hoofdstuk 4** zijn de verwachtingen van zowel jongeren met een mentale beperking (verstandelijke beperkingen, ontwikkelingsstoornissen en/of psychiatrische aandoeningen) in het speciaal onderwijs, als van hun ouders en schoolbegeleiders in de overgang van school naar werk beschreven met betrekking tot de mogelijkheid van de jongere om op de reguliere arbeidsmarkt werk te vinden. Daarnaast is onderzocht in hoeverre de jongeren, hun ouders en schoolbegeleiders in staat waren om de toekomstige werkstatus in te schatten en is vastgesteld wie deze toekomstige werkstatus het beste kon voorspellen. Meer dan de helft van de jongeren en de ouders en 37% van de schoolbegeleiders verwachtte dat de jongere in staat zou zijn om regulier werk te vinden, vergeleken met 39% van de jongeren die daadwerkelijk regulier werk vond gedurende de 18 maanden volgend op de Wajong-beoordeling. Jongeren met mentale beperkingen, hun ouders en hun schoolbegeleiders waren matig in staat om de toekomstige werkstatus van de jongere te voorspellen als ze reguliere werkmogelijkheden verwachtten. De verwachting van de schoolbegeleider was het enige perspectief dat significant voorspelde dat een jongere regulier werk zou vinden, waarbij de voorspelling door de ouders een klein aanvullend effect had en de verwachting van de jongere zelf nog een heel klein extra aanvullend effect; samen voorspelden ze in 71% van de

gevallen de juiste uitkomst. Geconcludeerd kan worden dat de verwachtingen van schoolbegeleiders en ouders waardevol zijn in het voorspellen van de werkuitkomst van de jongere. Daarom is samenwerking tussen schoolbegeleiders en ouders van belang om realistische verwachtingen te scheppen voor de jongere, zodat deze de best mogelijke werkuitkomst kan bereiken.

**Hoofdstuk 5** bevat een systematisch literatuuronderzoek naar de factoren die samenhangen met arbeidsparticipatie bij mensen met een autisme spectrum stoornis (ASS). Zeventien factoren, gecategoriseerd als ziekte-gebonden, persoonlijke of omgevingsfactoren, zijn gevonden in relatie tot deze werkuitkomst. Een cognitieve beperking was de enige significante en consistente voorspeller die duidelijk uit meerdere studies naar voren kwam. Functionele onafhankelijkheid en opname in een zorginstelling werden beide door één studie genoemd als voorspeller voor werkuitkomst. Voor de andere veertien factoren werden inconsistente of niet significante resultaten gevonden. Deze review laat zien dat er nog weinig wetenschappelijke literatuur beschikbaar is over voorspellers voor arbeidsparticipatie van mensen met ASS. Bovendien blijkt de kwaliteit van de studies die er zijn veelal onvoldoende en ontbreekt het vaak aan een focus op arbeidsparticipatie. Meer kwalitatief goede cohort studies zijn nodig, die focussen op arbeidsparticipatie als de primaire uitkomstmaat voor mensen met een autisme spectrum stoornis.

In **hoofdstuk 6** worden de resultaten beschreven van een studie naar factoren die arbeidsparticipatie, zowel werk vinden als behouden, voorspellen van jongeren met een autisme spectrum stoornis (ASS) en/of een aandachtstekortstoornis (ADD). Leefsituatie en motivatie bleken alleen van invloed te zijn voor jongeren met ASS, terwijl geslacht alleen van invloed was op de werkuitkomst van jongeren met ADD. Naast sociaal-demografische kenmerken (leeftijd, geslacht en leefsituatie), bleken ook de verwachtingen van de jongeren zelf met betrekking tot toekomstig werk van invloed te zijn op het vinden van werk. Daarom is het van belang voor professionals om rekening te houden met deze verwachtingen van jongeren met ontwikkelingsstoornissen bij de begeleiding naar werk. Aangezien de sociale context van jongeren met ontwikkelingsstoornissen een belangrijke rol speelt in het vinden en behouden van werk, is het ook van belang voor professionals die werken met deze jongeren om tijdens de begeleiding naar werk rekening te houden met deze context.

In **hoofdstuk 7** worden de voorspellers voor arbeidsparticipatie van jongeren met een lichte verstandelijke beperking beschreven. Persoonlijke factoren en, in mindere mate, sociale factoren bleken van belang te zijn in het voorspellen van arbeidsparticipatie. Motivatie, verwachtingen over toekomstig werk, leefsituatie en geslacht voorspelden arbeidsparticipatie van jongeren met een lichte verstandelijke beperking. De resultaten laten geen substantiële

verschillen zien tussen de voorspellers voor werk vinden en werk behouden. Met name persoonlijke factoren bleken van invloed te zijn bij het voorspellen van de werkuitkomst. Verwachtingen van de jongere zijn een belangrijke voorspeller voor zowel werk vinden als behouden; realistische verwachtingen vormen een voorwaarde voor zowel succesvol werk vinden als behouden. Van belang is dat ouders, schoolbegeleiders en re-integratieconsulenten deze jongeren helpen om realistische verwachtingen voor toekomstig werk te ontwikkelen. Factoren als motivatie en verwachtingen zijn beïnvloedbaar en daarom geschikt om op te nemen in interventies bedoeld om deze jongeren naar werk te begeleiden.

**Hoofdstuk 8** geeft een overzicht van de belangrijkste bevindingen van dit proefschrift, alsmede een discussie van de sterke en zwakke punten van het onderzoek en van de implicaties voor beleid en praktijk. Ook worden suggesties gegeven voor verder onderzoek. De inclusie van jongeren met een beperking op de arbeidsmarkt is wenselijk, zowel vanuit persoonlijk als vanuit maatschappelijk oogpunt. Voor een inclusieve maatschappij is het van belang te focussen op mogelijkheden in plaats van beperkingen. Dit betekent niet dat jongeren met een beperking de verantwoordelijkheid voor hun participatie in werk geheel zelfstandig moeten of kunnen dragen. De maatschappij als geheel heeft een verantwoordelijkheid om jongeren in staat te stellen en te faciliteren om werk te vinden en te behouden. Jongeren met een beperking kunnen alleen dan in regulier werk participeren als werkgevers, organisaties en bedrijven bereid zijn hen als werknemer aan te nemen en te ondersteunen in het werk. Vanwege hun kwetsbare arbeidsmarktpositie is het voor deze jongeren noodzakelijk om adequate ondersteuning te ontvangen, zowel vanuit formele bronnen, zoals door schoolbegeleiders, re-integratieconsulenten en werkgevers, als ook via informele kanalen, zoals van ouders, vrienden en burens.

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# DANKWOORD





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*Het Kenniscentrum Verzekeringsgeneeskunde (KCVG):* ook al viel mijn project officieel niet onder KCVG-verantwoordelijkheid, ik mocht toch regelmatig aansluiten bij de activiteiten van het KCVG. Naast de interessante en nuttige kennisuitwisseling tijdens deze bijeenkomsten, is het me ook steeds meer duidelijk geworden dat politiek minstens een net zo belangrijke rol speelt in de wetenschap als onafhankelijk onderzoek doen.

*De landelijke begeleidingscommissie:* Han Willems, Frans Nijhuis, Harriët Havinga, Dirk Verstegen en diverse vertegenwoordigers van Ministerie SZW, NVVA/AKC en CNV Jongeren hebben gedurende het project gefungeerd als klankbordgroep en waardevolle input geleverd gedurende de verschillende fasen van het project.

*De regionale begeleidingscommissie:* Jaap Kooiman (UWV), Simon Tiemersma (UWV), Harry Weisbeek (PrOREC), Ron van Gent (MKB), Jan Edzes (CEDRIS) en Hans van Ulsen (SoZaWe Groningen) hebben geadviseerd over de implementatie van het onderzoek en draagvlak gecreëerd binnen hun eigen organisaties. Hun enthousiasme om iets te betekenen voor jongeren met een beperking werkte inspirerend.

*De leden van de leescommissie:* prof. dr. H.W.E. Grietens, prof. dr. F.J.N. Nijhuis en prof. dr. J.H.B.M. Willems wil ik bedanken voor het lezen en beoordelen van het manuscript en de constructieve feedback, die ik daarop mocht ontvangen.

*Het Promotieteam:* Jac van der Klink, Johan Groothoff, Sandra Brouwer en later Michiel de Boer hielden me scherp. Het team was een rijke bron van inspiratie én commentaar. Jac toonde zich als eerste promotor betrokken bij het project en had altijd een vriendelijk en bemoedigend woord, ook als zaken iets minder soepel liepen. Hij was altijd bereid tot overleg en ik kon altijd binnenlopen. Ik heb de ruimte die hij gaf en het vertrouwen als zeer prettig ervaren. Johan riep al tijdens mijn studie Sociale Geografie dat ik op een dag zou gaan promoveren. Zijn vertrouwen in mijn kunnen en zijn enthousiasme hebben me gemotiveerd om ervoor te gaan. Zijn snelle en heldere reacties op de stukken werkten zeer stimulerend. Ik ben enorm dankbaar dat ik ondanks zijn pensionering in 2010 tot de afronding van het proefschrift gebruik mocht maken van zijn expertise en wijze adviezen. Sandra was mijn sparring partner en tegelijkertijd de baas. Zij was kritisch en tegelijkertijd ongelooflijk aardig. Van haar heb ik veel geleerd. Er bleken steeds nieuwe grenzen om te verleggen. Ook bewonder ik haar enorme prestatiedrang en doorzettingsvermogen, hoewel dat ook wel eens tot frustratie leidde. Er was altijd ruimte voor een goed gesprek en ik waardeer onze samenwerking zeer. Dankzij Michiel werden de statistische analyses technische hoogstandjes, maar ook hij bracht me wel eens tot wanhoop met zijn kritische vragen. Desondanks heb ik zijn inzet om de analyses tot een goed einde te brengen zeer gewaardeerd. Daarnaast heb ik mogen genieten van zijn geweldige didactische vaardigheden en ik heb zowel in Amsterdam als in Groningen veel van hem geleerd.

*Mijn collega's:* de collega's van Sociale Geneeskunde, Toegepast Gezondheids- onderzoek en Arbeid en Gezondheid hebben mijn promotietijd verrijkt. Door de vele activiteiten en vergaderingen, maar ook door de gesprekken tijdens de lunch(wandelingen) heb ik velen van hen iets beter mogen leren kennen. Marieke Meulenbeld heeft eindeloos veel vragenlijsten verstuurd en ingevoerd en ik ben dankbaar voor het vele werk dat zij mij uit handen heeft genomen. Thomas Koster heeft de vragenlijsten in Friesland ingevoerd en door hem heb ik een deel van de doelgroep beter leren kennen. Wijlen Willem Lok heeft de verschillende invoerprogramma's geschreven om een soepele dataverwerking mogelijk te maken. Roy Stewart ben ik erkentelijk voor zijn statistische adviezen aan het begin van het project en Truus van Ittersum voor de ondersteuning op het gebied van literatuuronderzoek. De ondersteuning van Lida en Janneke van het secretariaat in het maken en verzetten van de ontelbare afspraken was onmisbaar.

Geke Dijkstra en Daphne Kuiper stonden samen met Jitse van Dijk aan het begin van mijn wetenschappelijke carrière. Het enthousiasme van Geke en Daphne om onderzoeksprojecten op te pakken, mij te betrekken bij alle stappen van een onderzoek en hun aanmoediging om zelf dingen op te pakken, hebben mij overgehaald het wetenschappelijke pad in te slaan. Jitse van Dijk ben ik dankbaar voor zijn niet aflatende support. Hij waarschuwde mij voor de onvoorstelbare hoeveelheid werk die met een promotietraject gepaard gaat, dat het lijkt alsof daar nooit een eind aan komt, maar hij had ook altijd vertrouwen in de goede afloop. Met hem heb ik mijn allereerste (demografische) abstract en wetenschappelijke presentatie in het Engels voorbereid. Margriet Hielkema en Wendy Koolhaas hebben mij tijdens de verschillende ups en downs altijd een luisterend oor geboden ☺. Ondanks dat we alle drie harde werkers zijn, was er ook altijd ruimte voor gezelligheid. Wij hebben een stuk van ons leven gedeeld en ik ben ontzettend dankbaar voor zulke fantastische kamergenoten, ook voor hun bereidheid om als paranimfen op te treden.

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Wat het betekent om onderzoeker te zijn was niet voor iedereen altijd even duidelijk. Dit boekje maakt hopelijk een beetje tastbaar waar ik de afgelopen jaren zo druk mee ben geweest. Ik voel me rijk gezegend met zoveel dierbare mensen om me heen.

*Marcel* is mijn leven pas halverwege het promotietraject binnen komen wandelen, maar zonder hem waren de laatste jaren waarschijnlijk ongelooflijk zwaar geweest. Door hem is mijn stress gehalveerd en mijn vreugde verdubbeld en er is geen dag dat wij niet samen lachen en dankbaar zijn. Zijn onvoorwaardelijke liefde, vertrouwen en steun zijn ongelooflijk kostbaar voor mij.

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# CURRICULUM VITAE







### **ABOUT THE AUTHOR**

After having lived and worked in Chiang Mai, Thailand, for two years, Anja Holwerda decided to change her track and started an education with a high probability of contributing to a more equitable and just society. She graduated from the University of Groningen in 2007 with a master degree in Human Geography, and a specialization in Geography of Developing Countries. Her master thesis was entitled “Reproductive behaviour in the squatter settlements in Bacolod-City, the Philippines”.

While still studying, in 2004 she started working at the Department of Health Sciences of the University Medical Centre in Groningen (UMCG) as a research assistant for Applied Health Sciences Research (TGO). From 2007 to 2008 she worked as a researcher for the Municipal Public Health Services in the province of Flevoland on the Regional Public Health Status and Forecast report. During this time she still was involved in a project regarding a skills assessment of adolescents in special needs education at the UMCG. In 2008 she returned fully to the Department of Health Sciences at the UMCG to start her PhD studies. During her work at the UMCG she focused on young adults with disabilities and work outcome and conducted several projects in cooperation with the Social Security Institute. Furthermore she was involved in several other projects, for example regarding young adults with autism spectrum disorders and work.

In the past years she supervised several bachelor and master students in psychology and sociology during writing their thesis. During the first three years of her PhD studies she also had tutoring responsibilities for first year international medical students.

In 2012 she completed her Master in Epidemiology at the VU Medical Center in Amsterdam. Since December 2012 she is working as post doc at the Department of Health Sciences of the UMCG in research regarding the effectiveness of interventions targeting multiproblem families commissioned by the Instituut GAK. Furthermore, she is developing an assessment tool for municipalities (QuickScan WWB). This tool investigates the characteristics of applicants of welfare benefits to enable the municipalities to provide adequate and effective support to their applicants in their transition from welfare to work.

Her professional interests focus on vulnerable groups and the association with work and health, including young adults with (mental) disabilities and multiproblem families.

## PHD PORTFOLIO

### PhD training

Research Techniques	Period
Epidemiology of diseases	September – November 2011
Multilevel analysis	June/July, 2011
Logistic regression	May, 2010
Longitudinal data-analysis	March, 2010
Linear regression and variance analysis	November, 2009
Systematic reviews and meta-analysis	May, 2009
Principles of epidemiological data-analysis	February 2009
Epidemiological research: design and interpretation	January, 2009
General Research Competences	
Science Writing	May – September 2010
Project Management for Scientific Research	March/June, 2009; March, 2010
Presenting in English	June – September 2008
Reference Manager	June, 2008
Depth and breadth of knowledge	
Career orientation for PhD students and scientific employees	January – March 2013
Tutoring in English with International Students	June - November 2009
Working with small groups	August, 2008

### Scientific (international) presentations

Scientific (international) presentations	Period
EUPHA 6th European Public Health Conference, Brussels Oral: <i>"The effectiveness of interventions targeting multiproblem families: a systematic review"</i>	November 13-16, 2013
EPICOH international congress, Utrecht Oral: <i>"Predictors of Work Participation in Young Adults with Mild Intellectual Disability"</i>	June 18 – 21, 2013
10 <sup>e</sup> TBV-congres "Autisme en Werk" (on invitation), Amersfoort Oral: <i>"Voorspellers voor Werk van mensen met een Autisme Spectrum Stoornis"</i>	November 27, 2012
2 <sup>nd</sup> Work Disability Prevention and Integration International Conference, Groningen Oral: <i>"Autism and Work, a systematic review"</i> Oral: <i>"Work ability assessment in young adults with disabilities applying for disability benefits"</i>	October 22-25, 2012
Nederlandse Demografiedag Oral: <i>"Kenmerken van jongeren met een beperking en hun mogelijkheden voor participatie in werk"</i>	November 9, 2011
1 <sup>st</sup> Work Disability Prevention and Integration International Conference, Angers, France Poster: <i>"Characteristics of young disabled people and their opportunities for work participation"</i>	September 2-3, 2010
Nederlandse Demografiedag Oral: <i>"Opportunities for participation in work of young disabled people receiving a disability pension"</i>	October 22, 2009
Nederlandse Demografiedag Oral: <i>"Contraceptive use in squatter settlements in Bacolod City, the Philippines"</i>	October 9, 2007

**OTHER PUBLICATIONS**

1. Holwerda A, Brouwer S, Boer MR de, Klink JJL van der, Groothoff JW. (2012). What works with young disabled adults? Predictors for finding and maintaining work in the population of young disabled adults [*Wat werkt bij Wajongers? Voorspellers voor vinden en behouden van werk in de Wajongpopulatie*]. Groningen, Universitair Medisch Centrum Groningen/ Sociale Geneeskunde. ISBN: 978 94 6070 047 7
2. Holwerda A, Klink JJL van der, Groothoff JW, Brouwer S. (2012). Research in short: a systematic review of predictors for work participation in individuals with an autism spectrum disorder [*Onderzoek in het kort: Een systematisch literatuuronderzoek naar voorspellers voor arbeidsparticipatie van personen met een autismespectrumstoornis*]. Tijdschrift voor Bedrijfs- en Verzekeringsgeneeskunde 20(9): 375-376
3. Cuppen A, Dekker F, Brouwer S, Holwerda A, Groothoff JW, Klink van der JJL. (2010) Predictors of work participation of young adults with disabilities with autism spectrum disorder. [*Voorspellende factoren voor arbeidsparticipatie van Wajongers met Autisme Spectrum Stoornis*]. Nijkerk: Arbeidsdeskundig Kennis Centrum.
4. Holwerda A, Klink JJL van der, Groothoff JW, Brouwer S. (2010). Cohort of young adults with disabilities in the Northern Netherlands: characteristics of young adults applying for a disability benefit [*Wajong-cohort in Noord-Nederland: kenmerken van Wajongaanvragers*]. Tijdschrift voor Bedrijfs- en Verzekeringsgeneeskunde 18(10): 456-462
5. Achterberg T, Holwerda A, Verhoof E, Wind H, Brouwer S, Maurice-Stam H, Groothoff JW, Frings-Dresen MHW, Klink JJL van der. (2010). Young adults with disabilities at work: which factors are important for work participation of young adults with disabilities? [*Wajongers aan het werk: welke factoren kunnen van belang zijn voor arbeidsparticipatie van jonggehandicapten?*] Tijdschrift voor Bedrijfs- en Verzekeringsgeneeskunde (18): 52-58. i.c.w. AMC Coronel & Emma Kinderziekenhuis
6. Holwerda A, Brouwer S, Groothoff JW, Klink JJL van der. (2010). Searching for predictors of work participation of young adults with disabilities. [*Op zoek naar voorspellers voor arbeidsparticipatie van Wajonggerechtigden*]. DEMOS bulletin over bevolking en samenleving 26 (1): 11-12
7. GGD Flevoland. (2008). Regional Public Health Status and Forecast report: an overview of the public health, prevention and health care in the province of Flevoland [*Regionale Volksgezondheid Toekomst Verkenning (VTV); Een overzicht van de volksgezondheid, preventie en gezondheidszorg in Flevoland*]. Almere, GGD Flevoland.
8. Holwerda A, Kuiper D, Dijkstra GJ. (2007). Skills assessment multiple disabilities of adolescents from special needs education: opinions and ideas of teachers in special needs education [*UWV Verburg Assessment Meervoudige Handicap; Meningen en ideeën van docenten uit het PrO-REC onderwijs*]. Groningen, Sectie Toegepast Onderzoek Noordelijk Centrum voor Gezondheidsvraagstukken, Universitair Medisch Centrum Groningen.
9. Holwerda A, Kuiper D, Dijkstra GJ. (2007). Evaluation of skills assessment multiple disabilities of adolescents from special needs education [*Evaluatie UWV Verburg Assessment Meervoudige Handicap*]. Groningen, Sectie Toegepast Onderzoek Noordelijk Centrum voor Gezondheidsvraagstukken, Universitair Medisch Centrum Groningen.
10. Kuiper D, Holwerda A, Dijkstra GJ. (2005). Non-responses in screening for cervical cancer [*Non-response bij bevolkingsonderzoek naar baarmoederhalskanker*]. Groningen, Sectie Toegepast Onderzoek Noordelijk Centrum voor Gezondheidsvraagstukken, Universitair Medisch Centrum Groningen.



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