Work outcome in young adults with disabilities
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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; Boelzig 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.

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 & Redd acliff, 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; Kuriy an 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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General Introduction


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