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 workforce. 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 & Reddcliff, 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. They 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 workplace. 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).

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 & Selzer, 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-
Employment 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.
CHAPTER 8

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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