Consequences of success in pediatrics: young adults with disability benefits as a result of chronic conditions since childhood
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General discussion
As a result of improved efficacy of treatments and care for life-threatening pediatric conditions, the survival of children with serious congenital or acquired diseases in developed countries has increased during the last decades. With the increased rates of successful treatment and its positive effect on life expectancy the focus has shifted to the consequences of growing up with a chronic condition for the development in youth and the adaption to adult life. Along with continued efforts to improve survival rates in childhood chronic conditions, attention must be paid to how this population manages the challenge of growing up with a chronic somatic condition and their outcomes in adulthood. It is socially relevant to determine whether the (often hidden) consequences of the success in pediatrics affect the growing up and subsequent participation and independence in society. Therefore, the purpose of this study was to evaluate the psychosocial and emotional functioning in young adults with a Wajong benefit for a childhood-onset chronic somatic condition and the factors affecting their vocational success and wellbeing. Insights herein provide the opportunity to develop preventive and supportive interventions for young people with chronic illness to prepare for independence and work participation in adulthood. This allows us to maximize opportunities for young people, despite their condition and treatment, to participate in society. The main research questions of this study were as follows:

1. How does the psychosocial developmental trajectory (course of life) of young adults with disability benefits as a result of a somatic condition compare to that of a reference group?
2. How does the Health Related Quality of Life (HRQoL) and anxiety and depression of young adults with disability benefits as a result of a somatic condition compare to that of reference groups?
3. What are the Illness Cognitions (IC) of young adults with disability benefits as a result of a somatic condition? Is there an association of IC with HRQoL, anxiety and depression in this study population?
4. Is there a difference in the psychosocial development trajectory of young adults with and without a disability benefit?
5. What are the disease characteristics, work characteristics, and work motivation of young adults with disability benefits as a result of chronic conditions and the association of those factors and IC with the likelihood of being employed?
MAIN FINDINGS

1. COURSE OF LIFE (RESEARCH QUESTION 1 AND 4)
Growing up with a chronic condition poses potential risk to the psychosocial functioning and development. Findings of this study provide evidence that young adults with disability benefits with a chronic condition demonstrate delayed developmental trajectories across the transition to adolescence and adulthood with regard to developmental milestones compared to their peers from the general population. The course of life of our study group was found to be delayed since they proved to have achieved fewer milestones in all domains (social, autonomy and psychosexual development, substance use and gambling, anti-social behaviour), or to have achieved the milestones when they were older than their peers. Our results of the psychosocial developmental trajectory of young females with disability benefits because of JIA underline this finding. The young female beneficiaries achieved fewer milestones or reached the milestones at a later age than the peer group in the autonomy, social and psychosexual domain. Younger children with JIA seem to be able to keep up with peers at primary school level, but at middle or high school it seems to be more difficult to keep up with healthy peers. Possibly differences between children with chronic conditions and their peers become more salient in late childhood and adolescence, since developmental tasks occur more rapidly and peers becomes more important in this stage of life compared to parents and teachers. Hence, this may cause an age-associated increase of effects of the chronic illness on the development in young adulthood.

As far as we know this is the first study that compared the psychosocial developmental trajectory of young adult beneficiaries due to chronic conditions with the psychosocial developmental trajectory of young adults with chronic conditions who did not apply for disability benefits. The study among childhood cancer survivors (CCS) showed that young adult CCS with disability benefits scored more unfavourable in terms of milestones in autonomy, social and psychosexual development than CCS who did not apply for disability benefits. CCS with disability benefits scored less favourable than peers from the general population on 14 out of 22 milestones while the number was 6 for those without disability benefits. In young adults with chronic kidney diseases and thyroid diseases similar results were found. The young adults who did not apply for a disability benefit proved to have a more favourable development in terms of developmental milestones than those who had to apply for the disability benefit. These findings indicate that the developmental trajectory while growing up could be predictive of job participation in adulthood. More specifically, social activities with peers and having paid jobs in adolescence were associated with a
smaller likelihood of applying for disability benefits in young adulthood. Though causality cannot be proven between the achievement of milestones while growing up and applying for disability benefits in young adulthood, the fact that the developmental trajectory temporally preceded the disability benefits, gives an indication. It can be assumed that this is also the case for youth growing up with other chronic conditions. This possible causality between the achievement of milestones while growing up and applying for disability benefits in young adulthood is important information for the support for youth with chronic conditions. On the one hand, we expect and hope that stimulating the achievement of developmental milestones improves the likelihood of job participation. On the other hand, we could expect that CCS with disability benefits have to deal with serious medical consequences of the disease and treatment; too serious to be able to work and having led to a hampered developmental trajectory and lower educational level.

In sum, becoming an adult can be particularly challenging for youth with chronic health conditions since managing the disease or disability conflicts their age related developmental process, resulting in a higher risk for a delay in reaching independence in adolescence and young adulthood. The findings of this study are in line with previous findings, given that we already know that young adults who have grown up with a disease are at risk for a delayed CoL compared with the peer group. Particularly the CoL of patients with end-stage renal disease and survivors of childhood cancer was found to be hampered. However, our study concerned the part of those physical impaired young adults who are not able to earn a full salary as an effect of their condition and therefore applied for disability benefits. Given the fact that young adult CCS with disability benefits scored even more unfavourable in terms of milestones in their development than CCS who did not apply for disability benefits, we can consider young adults with a somatic disease or disability since childhood who have to apply for disability benefits as the most vulnerable group.

2. HRQOL AND ANXIETY AND DEPRESSION
The knowledge and measurement of HRQoL in young adults with chronic conditions is still at an early stage of development. This study helps to decline this gap in knowledge in particular for the vulnerable group of young adults with a disability benefit. We found worse HRQoL experienced by young adults claiming disability benefits compared with peers from the general population (chapter 3). The differences in HRQoL between the EMWAjong group and the reference group were substantial, especially in the physical and social domains. The considerable differences in the physical domains fit the assumption that the differences in HRQoL between people with a somatic condition and healthy
people are mainly based on physical limitations. However, the scores on the social domain indicate that social aspects also influence the HRQoL of young adults claiming disability benefits. They may feel restricted in social situations as a result of physical or emotional consequences of their conditions. This is undesirable, especially in adolescence, because close peer relationships are an important source of support for chronically ill or disabled adolescents at a time when they have to face developmental tasks and disease-related challenges. Obviously a chronic condition or disability can have large effects on well-being in young adulthood for those who have to apply for disability benefits, but much is still unknown.

Our study also points out that young adults with disability benefits scored significantly worse on feelings of anxiety as well as depression in comparison with the reference group. Almost double the proportion of the study group was at risk of an anxiety disorder, and for a depressive disorder the proportion is almost threefold, which are alarming numbers. Several studies found similar results in adolescents and young adults with chronic conditions that started in childhood. Our finding is also in line with results in adult populations. In the Netherlands, 40 percent of all adults with a chronic illness or disability had a high risk of psychiatric problems such as anxiety or depression. This percentage was significantly higher than the 20-25% found in the general Dutch population in 2005.

Individual differences in emotional functioning and psychological distress may be related to the adjustment of young adult beneficiaries in young adulthood. Also, previous research has shown that the course of life of young adults with a chronic condition is related to their quality of life. In particular, the social development appears to be associated with the perceived quality of life in young adulthood. Moreover, emotional functioning and psychological distress seems to be related to work participation of young adults with disability benefits. Young adults with disability benefits who participated in the work force reported a better HRQoL than those without successful work participation. And those who have ever worked feel less depressed than young adults with disability benefits who have never worked successfully at the labour market. For this reason, and also in the light of the increasing number of young adults with a chronic disease reaching adulthood because of medical advancements, it is very important to pay attention to the emotional consequences of chronic somatic conditions in an early stage.

3. ILLNESS COGNITIONS
This study provided the first findings on generic illness cognitions of young adults with a childhood-onset somatic condition (chapter 5). In line with pre-
vious studies in adult populations, the used questionnaire showed strong internal consistency and reliability in our study group. A rather high level of acceptance and perceived benefits was found, indicating that the majority of the young adults with disability benefits in this study have learned to live with their illness or disability and even perceive some long-term beneficial consequences of their conditions. The fact that their chronic condition has limited them since childhood may have influenced their acceptance and perception of the possible benefits in a positive way. Helplessness in contrast, a cognition with a substantial negative impact, was present in more than half of the respondents. This indicates that the young adult beneficiaries in this study feel an inability to control a particular situation and emphasize the negative aspects of their condition in daily functioning, which is related to deterioration of their physical and psychological functioning.\textsuperscript{24,25}

Furthermore, our findings indicate that the illness cognitions of young adult beneficiaries are relevant for their psychological functioning. The illness cognitions acceptance and helplessness were associated with HRQoL as well as with feelings of anxiety and depression in young adults with a disability benefit because of a chronic somatic condition. Though the direction of the correlation could not be established, it is plausible to assume that acceptance of the illness or disability, learning to live with it, influences HRQoL positively and reduces feelings of anxiety and depression. Lebovidge et al\textsuperscript{26} found similar results among youth with chronic arthritis - a more positive attitude toward illness was associated with lower levels of anxiety and with depressive symptoms. However, depression and anxiety can affect cognitions as well. Stronger feelings of helplessness appeared to be associated with worse HRQoL and higher levels of anxiety and depression. Young adult beneficiaries experiencing a great deal of helplessness are more likely to see their futures in adulthood as uncertain which could be a risk factor for the development of psychological distress over time. Again, the direction of the correlation could not be established.

The finding that illness cognitions of young adult beneficiaries are associated with their emotional well-being is also in line with studies in adults with chronic illness.\textsuperscript{27-29} The modest contribution of disease-characteristics to HRQoL, anxiety and depression, supports the notion that there is only a weak relationship between biomedical parameters and psychosocial well-being. Illness cognitions on the other hand, do contribute considerably to individual differences in young adult beneficiaries regarding their psychosocial well-being and possibly long-term adjustment. This means that health care providers are increasingly called upon to help children, adolescents and young adults to cope with the psychological and social aspects of a chronic condition. To do so it is important to assess the attitudes and cognitions toward illness among youth and to develop
interventions to help youth cope with their conditions, and providing interventions to accept their situation.

4. WORK

Although some young adults with disability benefits as a result of chronic conditions since childhood make a good adjustment to working life, many others struggle with the impact of their condition on work participation. These young adults are at the very beginning of their vocational career, but they already have trouble with entering and staying at the labour market (chapter 7). This study found differences between young adults with disability benefits who are successful at the work force compared to those who are not, regarding the need for support at work, feelings of helplessness, parents who consider work important for their child and work motivation.

We found that only a small minority (46.1%) of the young adults with disability benefits had a paid job during high school. This is in line with other studies: youth with disabilities typically have less involvement in work experiences than their peers during high school and often encounter barriers when striving for independence. In line with this, it is alarming that many of the young adults with a range of chronic conditions or disabilities do not work as much as they are able to in young adulthood. Even though all respondents in this study are declared capable of work, only a minority of the respondents have had a paid job since they applied for disability benefits (38.2%). In other words, the majority ‘grows into disability benefits’ and is at risk of worse vocational outcomes regardless of the specific health condition.

Many young adults with disability benefits – successful in the work force or not – reported to need work adjustments to be able to participate in the work force. Adjusted working hours, adjustment in the work place and transport to work were the most frequently mentioned adjustments, especially by those unsuccessful in the work force. The need for support at work was significantly higher in those who have been successful at the labour market. Further, young adults without successful work experience reported significant more feelings of helplessness, a cognition with a substantial negative impact. This might indicate that the young adult beneficiaries without work feel an inability to work or to get employed. Also, the young person’s own motivation turned out to be an important ingredient in achievement in occupational outcomes. Those with a firmer work motivation are more likely to participate successfully on the labour market. This is in line with studies which have found that having high aspirations is associated with better employment outcomes in early adulthood, independently of other characteristics such as parental background or schooling. Among the young adults with chronic conditions, motivation likely leads to greater initiative.
to search for employment. In addition, motivated people receive more guidance or support to find a job, and coaches and employers react positively to motivated individuals. An explanation for a lower motivation may lie in the fact that the young adults do not consider themselves as capable of work and, therefore, do not have the ambition to be employed. Young adults with parents who indicate work as important for their child were significantly more successful in the labour market. It is unknown if parents who attach less importance to the work participation of their child do so because of realistic expectations of the child’s capabilities or just because of lowered expectations and overprotection. There seems to be a delicate balance between the importance of parental support for disabled young people on the one hand, and their occasional tendency to underestimate their youngster’s capabilities on the other.

Our results didn’t give a clear picture of factors associated with successful employment and therefore suggest that there is a complex relationship among demographic factors, treatment, and psychosocial functioning and employment. Some factors found in this study are not changeable, but other factors like the level of support, motivation and illness cognitions can be influenced. This study gives starting points for the development of interventions which could lead to successful work participation. Screening on moments of transition e.g from primary school to secondary school, and from education to employment, can give insight in the developmental pathway of youth with chronic conditions, including vocational readiness. By identifying the vocational development and the factors that influence the work participation of youth with chronic conditions, a better match between work ability, work interventions and work demand can be found. Also, work interventions aimed at vocational training (including work objectives, defining the work related need for support, coping strategies, occupational balance, finding a suitable job) and realistic career goals should be developed and tested.
Chapter 2
Psychosocial developmental trajectory of young adults with disability benefits because of a chronic somatic disease since childhood

<table>
<thead>
<tr>
<th>Purpose</th>
<th>Sample characteristics</th>
<th>Measures</th>
<th>Main results</th>
</tr>
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</table>
| Young adult beneficiaries N=415: | | Course of life questionnaire (LVJV) | - Young adults with disability benefits had lower scales scores than the reference group in all five psychosocial developmental domains: autonomy development, social development, psychosexual development, substance use and gambling, antisocial behaviour.  
- Young adults with disability benefits scored less favourable than the reference group on 27 out of the 38 psychosocial developmental milestones (item-level).  
- In conclusion, young adult beneficiaries with somatic limitations since childhood are at risk of a delayed course of life. The differences between young adults with disability benefits and the reference group are substantial. |
| Age at study: M=25.0 yrs (22.5-30.9)  
64% female | | | |
| Reference group N=508: | | | |
| Age ate study: M=24.2 yrs (18.0-30.9)  
53% female | | | |

Chapter 3
HRQoL, anxiety and depression of young adults with disability benefits because of a chronic somatic disease since childhood

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<tr>
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<th>Sample characteristics</th>
<th>Measures</th>
<th>Main results</th>
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</table>
| Young adult beneficiaries N= 415: | | RAND-36 Hospital Anxiety and Depression Scale (HADS) | - Young adults with disability benefits reported worse HRQoL than the reference group in all eight domains except for General mental health.  
- Young adults with disability benefits reported higher levels of anxiety and depression than the reference group. In addition, compared to the reference group a higher percentage was at risk for an anxiety (29.7 versus 17.6 percent) and depressive disorder (17.0 versus 6.0 percent).  
- HRQoL, anxiety and depression were associated with the course of the disease and the use of medical devices (those with a stable or positive course of disease reported a better physical and mental HRQoL and lower levels of anxiety and depression; those using medical devices reported worse physical HRQoL, but better mental HRQoL and less anxiety and depression.  
- In conclusion, young adult beneficiaries are at risk of worse HRQoL and emotional well-being. |
| Age at study: M=25.0 yrs (22.5-30.9)  
64% female | | | |
| Reference group RAND-36 N=508: | | | |
| Age ate study: M=24.2 yrs (18.0-30.9)  
53.0% female | | | |
| Reference group HADS N=182: | | | |
| Age ate study: M=27.1 yrs (22.0-30.0)  
62.1% female | | | |
Chapter 4
HRQoL and psychosocial developmental trajectory in young female beneficiaries with Juvenile Idiopathic Arthritis

Young adult female beneficiaries with JIA N=43:
Age at study: M=25.8 yrs (SD=2.3)
Reference group of females N=269:
Age at study: M=24.3 yrs (SD=3.8)

Course of life questionnaire (LVJV)
RAND-36
Hospital Anxiety and Depression Scale (HADS)

- The beneficiaries reported worse HRQoL than the reference group in all eight domains of the RAND-36 except the domains Mental Health and Role limitations due to emotional problems.
- The beneficiaries achieved fewer milestones or achieved the milestones at later age than the reference group, in the autonomy, social and psychosexual domains.
- In conclusion, young females with JIA who have to apply for disability benefits are at risk for impaired HRQoL and a delay in their psychosocial developmental trajectory.

Chapter 5
Illness cognitions of young adults with disability benefits because of a chronic somatic disease since childhood

Young adult beneficiaries N= 415:
Age at study: M=25.0 yrs (22.5-30.9) 64% female

Illness Cognition Questionnaire (ICQ)
RAND-36
Hospital Anxiety and Depression Scale (HADS)

- Respectively 90.2%, 83.8% and 53.3% of the young adults with a disability benefit experienced feelings of acceptance, benefits and helplessness.
- Several disease-characteristics (the nature of the disease process over time, the use of medication, the use of medical devices, tiredness, limitations to sit, perceptible disease/disability) were associated with IC; particularly those with a positive/stable course of illness scored higher on acceptance and lower on helplessness.
- Illness cognitions were associated with well-being; more acceptance and less helplessness were associated with better mental and physical HRQoL and less anxiety and depression.
- In conclusion, IC of young adult beneficiaries are associated with emotional well-being.

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RAND-36
Hospital Anxiety and Depression Scale (HADS) | - The beneficiaries reported worse HRQoL than the reference group in all eight domains of the RAND-36 except the domains Mental Health and Role limitations due to emotional problems.
- The beneficiaries achieved fewer milestones or achieved the milestones at later age than the reference group, in the autonomy, social and psychosexual domains.
- In conclusion, young females with JIA who have to apply for disability benefits are at risk for impaired HRQoL and a delay in their psychosocial developmental trajectory. |
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Chapter 6

Psychosocial developmental trajectory of survivors of childhood cancer with and without disability benefits

<table>
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<tbody>
<tr>
<td>Childhood cancer survivors (CCS) with disability benefits N=53</td>
<td></td>
<td>Course of life questionnaire (LVJV3)</td>
<td>• Compared with the reference group, both CCS with and CCS without disability benefits had lower scales scores in the social and psychosexual domain.</td>
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<tr>
<td></td>
<td>without disability benefits N=313:</td>
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<td>• CCS with disability benefits had lower scale scores in the social and psychosexual domain than CCS without disability benefits.</td>
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<td></td>
<td>Age at study: 17.7 – 31.1 yrs</td>
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<td>• CCS with disability benefits scored less favourable than the reference group on 14 out of 22 psychosocial developmental milestones.</td>
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<tr>
<td></td>
<td>Age at diagnosis: 0.0-17.0 yrs</td>
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<td>• CCS without disability benefits scored less favourable than the reference group on 6 out of 22 psychosocial developmental milestones.</td>
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<tr>
<td></td>
<td>Diagnosis:</td>
<td></td>
<td>• In conclusion, CCS with an unfavourable developmental trajectory while growing up were more likely to apply for disability benefits in adulthood than CCS with a more favourable development.</td>
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<tr>
<td></td>
<td>- with benefits 40.4% CNS cancer</td>
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<tr>
<td></td>
<td>- without benefits 5.4% CNS cancer</td>
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<tr>
<td></td>
<td>Gender:</td>
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<td></td>
<td>- with benefits 62% female</td>
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<td>- without benefits 49% female</td>
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<tr>
<td>Reference group N=508:</td>
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<tr>
<td>Dutch peers without a history of cancer</td>
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<tr>
<td>Age at study: M=24.2 yrs (18.0-30.9)</td>
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<tr>
<td>53% female</td>
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Chapter 7: Work characteristics, illness cognitions and work motivation of young adults with disability benefits and the association with the likelihood of being employed.

Purpose: To investigate the work characteristics, illness cognitions, and work motivation of young adults with disability benefits and to assess the association with the likelihood of being employed.

Sample characteristics:
- Young adult beneficiaries N=353: of which information about work was available
  - Age at study: M=25.0 yrs (22.5-30.9)
  - 66% female
- Successfully employed N = 135 (38.2)
- Unsuccessfully employed N = 218 (61.8)

Definition successfully employed: having a paid job at least 12 hours a week during at least 6 months since they applied for disability benefits.

Measures:
- Work characteristics
- The Illness Cognition Questionnaire (ICQ)
- Work motivation (subscale of the Work and Life Attitudes Survey).

Main results:
- In total, 38.2% were successfully employed since they applied for disability benefits. Many young adults – whether successful or not in the work force – reported to need work adjustments, in particular adjustment in working hours (43.2%). Almost half (46.1%) of the young adults with disability benefits had a paid job during high school.
- Compared to unsuccessfully employed beneficiaries, a greater proportion of successful beneficiaries reported a need for support at work (32.1% vs 21.6%), successful beneficiaries reported less feelings of helplessness and had a greater work motivation, and a greater proportion of the parents attached importance to work for their child (89.6% vs 64.8%).
- While controlling for socio-demographic and disease characteristics, only the extent to which parents consider work important for their child remained significant in predicting successful employment.
- In conclusion, there is a complex relationship among disease characteristics, work characteristics, illness cognitions, work motivation and employment in young adults with disability benefits as a result of a chronic condition.
METHODOLOGICAL CONSIDERATIONS AND DIRECTIONS FOR FUTURE RESEARCH

METHODOLOGICAL CONSIDERATIONS

The EMWAjong-study elaborates on the current literature by focussing on the consequences of growing up with a chronic disease on psychosocial development, emotional well-being and employment in a population of beneficiaries with somatic conditions. The use of a uniform measurement at one time point, including different diagnosis groups with age of the respondents ranging from 18-30 years old, led to a comprehensive set of information of a relatively large sample of Wajong beneficiaries with somatic conditions. However, the results of the EMWAjong study must be considered in light of a number of limitations. First of all, the cross-sectional design of this study made it impossible to distinguish ‘cause and consequence’. Moreover, this study is not inclusive, there may be other factors that affect psychosocial functioning, emotional well-being and labour participation, for example the amount of received support, personality, other medical characteristics and attitudes towards employment.

With regard to the generalizability of the results it should be noted that the act Wajong is a Dutch benefit; most countries have no specific benefit for young disabled people. Therefore, it is advisable to be cautious and conservative while interpreting results of this study and extrapolating the findings to a larger population or to other countries. In this regard, the response rate of 20% is also a limitation, though it is important to notice that this is a very average response rate among young adults with disability benefits. Due to the growing interest in the labour market position of young adults with disability benefits, they are often invited to participate in several studies. Moreover, it is possible that respondents did not fill in the questionnaire because the invitation letter was sent by the benefits agency. Although the questionnaire was anonymous, beneficiaries might be afraid of losing their benefit. Alternatively, those with better psychosocial functioning or emotional well-being might be less eager to participate because of reluctance to feel stigmatized. In addition, among those who did participate social desirability could be a threat to the validity of the results in this study. As a result of the non-responders bias there may be an under- or overestimation of the results of this group and this limits the possibility to generalize our findings to the whole group of young adults with a chronic somatic condition. As a result of the need to respect the privacy of the beneficiaries, we were lacking the information regarding the non-responders to be able to pronounce upon a potential selection bias.

Regarding the generalizability of the results, it should also be noted that, not all young adults with chronic conditions apply for a disability benefit. Individuals
with an adequate level of independent functioning may not deem it necessary to apply for a disability benefit. It is unknown which part of the young adults with a chronic condition in the Netherlands apply for disability benefits. As we only included those young adults applying for a disability benefit, it is not possible to generalize our results to young adults with chronic conditions not applying for disability benefits. And additionally, our study focussed on those who applied for disability benefits because of somatic conditions. For that reason the results cannot be extrapolated to other groups with a Wajong benefit.

One should realize that the conclusions were based on the results found in a highly heterogeneous study population, consisting of numerous diagnoses with various levels of illness severity and consisting of young adults suffering from more than one medical condition. Due to the study design we were not able to determine whether the conclusions are applicable to specific disease categories. Also, the variety of chronic somatic conditions in the research population prevents the identification of high risk subpopulations within this population of young adult disability benefit recipients. Although we did control for some disease characteristics in this study, disease characteristics merit greater attention as potentially mediating variables in future research.

Another methodological limitation concerns the questionnaire used. It was developed for the EMWAjong-project and included validated instruments, with adequate psychometric properties \(^{12, 24, 40-44}\), as well as a number of questions adapted from other questionnaires \(^{45}\), and questions developed by the researchers. For the questions developed by the researchers no information regarding reliability and validity was available. The clarity and applicability of the questions was pre-tested by 10 respondents who met the inclusion criteria, and based on their comments, the questionnaire was adjusted. The final questionnaire consisted of six parts which contained multiple questions. The length of the questionnaire could have led to a lower completion rate and poorer quality responses as a result of respondent fatigue. Furthermore, to complete the questionnaire the respondents must have been able to read and understand the questions. This could have resulted in an underrepresentation of respondents with a low education level.

The measurement of work participation is complicated. We used the common definition of work participation; 12 hours per week for an uninterrupted period of 6 months. However, it is known that some young adults with disability benefits work less hours a week for a period of years or several periods shorter than six months. Another definition of work participation might have given other results. In addition, the prediction of successful work participation point out to be problematic since the possible relationship of various factors with work participation is highly complex, and we could only study a number of possible determinants.
The use of a self-report measure and a single informant increased the possibility of finding relations that are in fact the result of shared method variance, meaning that the association between constructs may be due to the method used. In future research this problem could be solved by using a combination of for instance self-report and observations and multiple informants. In addition, it is worth considering alternative methods of data collection. In this study a quantitative research method was used. However, qualitative methods enable exploration of the complex processes and experiences of young adults and could offer a deeper understanding of the everyday challenges of youth growing up with chronic conditions.

DIRECTIONS FOR FUTURE RESEARCH

Future research should focus on the very long-term effects of growing up with a chronic somatic condition. It is socially relevant to know how those children with a chronic somatic condition since childhood go further in the rest of their (adult) life. It is important to study whether the disparities between those with and those without a childhood onset somatic condition change when growing older. For example, from dialysis patients with end stage renal disease since childhood it is known that after the age of 30 years, a substantial proportion of nearly two-third had remained employed, despite their deteriorating physical condition. This could also be the case for other groups. It is important to monitor youth with chronic conditions – with and without benefits – over a (life) long period. It is also important to identify those most likely to develop difficulties and which factors are associated with these difficulties. This study gave a point of departure. There are, however, other interesting factors that may affect the psychosocial development, the emotional well-being, social participation and labour participation, for example, coping skills, personality, the amount of received support, attitudes towards employment, parental support. Research on the relation of medical characteristics with developmental trajectory and disability benefits is also warranted.

Future research should also focus on whether stimulating the achievement of developmental milestones while growing up will create conditions for a better labour market position. We need longitudinal research focussing on life course into adulthood and person–environment interactions. In addition, we need to know who would benefit from support and what kind of support is most effective, specific to the psychosocial development, quality of life and work force participation. More consistent, early and rigorous monitoring of the child in a lifespan perspective is needed. Screening on moments of transition can give insight in the developmental pathway of youth with chronic conditions. This should be a component in medical guidelines.
Screening on moments of transition e.g. from primary school to secondary school, and from education to employment, can give insight in the developmental pathway of youth with chronic conditions, including vocational readiness. By identifying the vocational development and the factors that influence the work participation of youth with chronic conditions, a better match between work ability, work interventions and work demand can be found. Also, work interventions aimed at vocational training (including work objectives, defining the work related need for support, coping strategies, occupational balance, finding a (suitable) job) and realistic career goals should be developed and tested. The development of an accurate and complete database on the employment position of young persons with chronic conditions over years, disaggregating them for e.g. type and severity of disability, support needed, support utilized, job characteristics, gender and age is warranted. These statistics should be updated annually, to be used in longitudinal studies that analyze the extent to which chronic illness affects the work participation and amount of support needed.

In sum, the whole area of work is under-researched and lacks funds to do so. The outcomes for disabling conditions arising out of childhood need to be known, as this may have direct influence on the planning of medical interventions and availability of support. Also, insight in the influence, the role and the challenges of parents of a child with a chronic condition is important. With the ACTION study we made a good start in what is a very sensitive and complex area. Further research into the field of the complex association between parental functioning and child adjustment outcomes is strongly recommended. It is hoped that our increasing knowledge will benefit all children and youth with health-related problems of today who are the adults of tomorrow.

REFLECTIONS

The results of this study add to the understanding of the transition to adulthood and adult experiences and outcomes of young adults with disability benefits as a result of a childhood-onset chronic illness or disability. The psychosocial development, emotional wellbeing and economic position of this group are affected negatively. Three general interpretations in line with the findings may be drawn.

REALISTIC EXPECTATIONS

The concept of emerging adulthood is important when looking at realistic social outcomes and independence for all youth, but especially youth with chronic conditions. Emerging adulthood is a phase of the life span between adolescence and full-fledged adulthood which encompasses late adolescence and early adult-
Emerging adulthood is the period where adolescents become more independent and explore various life possibilities - trying out various possibilities in love, work, living situations, and world views. During emerging adulthood 'twenty-somethings' struggle with identity explorations; instability; being self-focused and feeling in-between - neither adolescent nor adult; and possibilities. It is a period when hopes flourish and young people have unparalleled opportunities to transform their lives. Our society expects young people to complete school, find satisfying work, develop social networks, contribute to the maintenance and support of households, and participate as citizens in communities, all within a certain timetable. The question is whether this is a realistic expectation for people grown up with a chronic condition, given the fact that we know that these young people develop more slowly or do not reach all developmental milestones. Initial stresses associated with diagnosis, ongoing stresses from treatments and social disruption, and changes in plans and expectations about the future can be a substantial challenge to social and emotional wellbeing and outcomes in adulthood. Young people with disabilities and chronic conditions may have more difficulties because extra time may be needed to complete school and prepare for work; they may be socially isolated; and families, professionals, and community members may have low expectations of them. Moreover, for young adults growing up with a chronic condition trying out different developmental steps at the same time is difficult. The achievement of one developmental step over time is often a challenge in itself. They may spend more time trying on different roles and identities. Their medical conditions or disabilities may impact how quickly they mature physically, cognitively, and socially. Also, most of the young adults with chronic conditions need support from parents and professionals. Thus the pace of their developmental trajectory and the exploration during emerging adulthood is partly related to the support they receive. However, young people growing up with chronic conditions are mostly gaining their independence but not as quickly as young people without a childhood onset. It is important that our society provide the extra time and appropriate support they need to walkthrough their steps along their diverging developmental pathways. Therefore, the treatment and support must focus on their life course, person–environment interactions and experiences and opportunities needed for a positive development and participation in society.

MEANINGFUL PARTICIPATION
The existing view on youth with chronic conditions or disabilities is largely focused on medical optimization and the achievement of indicators of adulthood such as finishing education, starting a career, leaving home. Many of these indicators are normative in nature resulting in disadvantaged or 'negative' out-
come profiles, or at least a delayed trajectory. Although it is very important
to know the developmental trajectory of young people growing up with physi-
cal challenges in order to respond to their needs, it is of utmost importance to
avoid a deficit-focused approach. All children, including those with physical
limitations, are in a constant state of ‘becoming’ and the outcome is unknown.

Therefore, we need a strength-based approach focussed on positive and indi-
vidualized outcomes such as citizenship and meaningful participation that
are significant to all youth with chronic conditions or disabilities and their fam-
ilies. The interpretation of meaningful participation varies from person to per-
son. Therefore, we need to encourage youth to explore their possibilities and
preferences for education, employment, or other activities in a safe, supportive
and stimulating environment right from the start. It is through positive, devel-
opmentally appropriate life experiences throughout their childhood and ado-
lescence and regular opportunities for participation and inclusion that youth can
prepare for a successful and meaningful participation in adult life.

INDIVIDUALIZED CARE
In order to realise meaningful participation for youth with somatic conditions,
we need to focus on person-centred and tailored actions for this vulnerable
group. The Wajong population is highly heterogeneous consisting of numerous
diagnoses and each diagnose can have several levels of illness severity. Besides,
most young adults with disability benefits have more than one condition and
every individual has personal needs and preferences. An approach that’s helpful
for one person could be unsupportive for another. Consequently, various levels
or types of care, support and interventions may be needed. We should ask chil-
dren, adolescents and young adults with chronic conditions, at any time, about
their preferences and needs for support – and should not decide for them what
is needed. Individualized person-centred care, strengthening independence
and wellbeing from childhood, throughout adolescence and into adulthood,
should get our attention during adolescence and emerging adulthood in clin-
ical practice.

CLINICAL AND SOCIETAL IMPLICATIONS
In order to maximize opportunities for young people growing up with chronic
somatic conditions and to realise meaningful participation in society several
adjustments – in different areas, on different levels – in the care for those with
a childhood onset are needed.
PHYSICAL, PSYCHOSOCIAL AND EMOTIONAL CARE IN A LIFESPAN PERSPECTIVE

The approach in the medical context is frequently focused on the physical consequences of the somatic condition and its treatment instead of the patient’s emotional well-being and social outcomes. In our traditional biomedical approach the focus, appropriately, is on stopping, limiting or at least controlling the disease, for example, ensuring acceptable blood glucose levels in diabetes mellitus, or ‘fixing’ the impairments in persons’ body function and structure, for example, reducing the incidence of bladder infections in spina bifida. To do so, pediatricians measure and weight their patients to monitor the physical growth and health of their patients. There are growth curves and other markers which can indicate whether there is a deviation from the norm. However, the results of this study show that all health care providers currently treating children with chronic conditions should pay systematic attention to their medical but also to their emotional and psychosocial development as well. In other words, health care providers’ awareness of the effect of growing up and living with childhood illness and disability in all aspects of life is essential. They can incorporate physical, psychosocial as well as emotional outcomes by aiming at optimal living and participation in society.

If possible, it is important to monitor the psychosocial development and symptoms of psychological distress in an early stage, prior to adolescence when differences in for example autonomy behaviour may appear more salient. This would provide a chance to recruit patients with significant risks for an unfavourable psychosocial or psychological outcome for interventions to avert possible negative consequences, such as social problems, academic problems or the development of psychopathology. But also in adult healthcare, attention to possible risks of consequences of the condition and its relation to well-being and social participation seems sensible for people with chronic conditions. This is particularly important since it is known that patients with a childhood-onset are at increased risk for a delayed course of life and of educational, vocational, and social problems during lifespan. Therefore, the focus should be a lifespan perspective of care.

To achieve optimal support for these young people, health care workers should have knowledge about possible gaps in the course of life and the emotional and social wellbeing of their patients. In order to do so, systematic assessment of the ongoing emotional, psychosocial, educational, and vocational needs during the developmental process should be an integral component of the comprehensive care of chronically ill or disabled patients with a childhood-onset. To systematically assess psychosocial and emotional functioning and to monitor this over time Patient Reported Outcomes (PROs) can be used by profes-
sionals in pediatric and adult health care through computerized and web-based applications. By using patient reported outcomes (PROs) such as developmental milestones, emotional well-being and HRQOL questionnaires in daily clinical practice care, physicians, psychologists, and nurses can adequately identify the specific problems in different domains of people growing up with chronic conditions. Systematically reporting PROs to the pediatrician during the consultation can facilitate communication about HRQOL and the psychosocial and emotional development. When psychologists and physicians work together, PROs can be used to closely monitor youth with chronic illnesses in a multidisciplinary context and referral to psychosocial interventions can be better facilitated. This developmental care should be continued during the health care transition and in adult health care.

THE ROLE OF HEALTHCARE PROVIDERS
Health care providers – e.g. physicians, nurses, psychological care givers – are in a good position to guide their patients in dealing with a childhood onset health condition while aiming at social participation and life satisfaction. By guiding the patient and their family members through the important tasks of childhood, adolescence and young adulthood, the health care providers can set the stage for the patients to live a satisfactory life. They can help the youngsters and their families to develop positive attitudes and realistic expectations about their abilities in a society where self-sufficiency and independence receive widespread recognition and social endorsement. Health promotion, healthcare regimen education, peer contact, early vocational awareness, education, alternatives to work, and leisure time use could be topics to discuss. There are also needs for sex education, preparation for parenthood, and genetic counselling.

To provide appropriate guidance of the children with a chronic condition and their families, health care providers should view the patient in the context of his or her life; as an integrated individual in a system of family, friends, school, work and society. However, owing to the continuous specialization in health care and lack of time, the main focus and goals of treatment in pediatrics are focussed at the control of a disease and its symptom in isolation. Therefore, it is recommended that all physicians apply the World Health Organization’s International Classification of Functioning, Disability and Health framework which focuses on functioning in society. This will help them understand youths’ functioning beyond the medical diagnosis, to address the sometimes complex interaction between person and environment and to develop a comprehensive care plan based on the youths’ needs in paediatrics and beyond. In rehabilitation care this approach is more common and could serve as an example in pediatric care more generally.
Consequently, there is a need for more effective training of healthcare professionals working with persons growing up with a childhood condition. Pediatricians need competences such as skills in ‘communication’, ‘collaboration’ and ‘health advocacy’ as much as their ‘medical expertise’ to help youth with chronic conditions. Educational training programmes for health care professionals in pediatrics and adult health care are needed to create an optimal blend of knowledge, skill, attitudes, and experience in the medical and social issues of persons growing up with a childhood condition. This investment might be well applied, as the health care should be more efficient and effective. Provided that such investment secures better outcomes on individual level and - in the end - societal level, investments should pay off in the long run.

HEALTH CARE TRANSITION

The ‘lifespan perspective in a continuum of care’ becomes increasingly important when young people with chronic conditions have to leave pediatrics and transfer to adult medicine. Although moving on to adult care is seen by most youth, parents and health care providers as a positive step on the road towards adulthood, virtually all studies on youth with chronic conditions or disabilities indicate that the reality is that transition remains problematic. It is important to warrant a health care continuum serving the development of people with a childhood onset. Next to the transition in care all other topics that have been discussed in pediatric practice must continue in adult health care since most patients are developmentally delayed at the moment of the transfer. In line with all the transitions young people with a childhood onset have to make, the process of health care transition should start early with a lifespan perspective to development. Also, special attention should be paid to the transfer readiness. Not all adolescents are ready for the transfer to adult health care at the same time. Repeated discussions on the health care transition could further enhance the readiness for the transfer to adult care. In addition, valuing the personal characteristics of youth and identifying their needs, wishes and aspirations for health care and societal future is very important to provide effective transitional care in an individualized way.

Due to the cultural and organizational differences between pediatric and adult services there are many potential barriers to achieve a successful health-care transition. Van Staa et al. noticed a discrepancy between the priorities of health care professionals in the transition from pediatrics to adult care and the way in which transition of care is being practiced at the moment in the Netherlands. According to the health care professionals, promotion of self-management and social participation are important areas for improvement. Structural interventions aimed at preparation for transition of care and promotion of
more independence are rare. Essential elements of a transition program such as transition protocols, individual action plans, and the use of a transition coordinator or transition clinic need to be implemented. Tailored, joint plans are the basis for sound health care planning complemented with a focus on education, social integration, independent living, vocational training, and employment. Sound transition planning for young people with chronic conditions can integrate these areas in health care by connecting pediatric and adult health care. During this process the health care team will play a role both as a referring care giver and as a coordinator of services for the child and family.

**FAMILY**

*Family perspective*

Another important issue in health care for young people growing up with chronic conditions is the young adult within the family perspective. Pediatric conditions affect the entire family. The experience of a pediatric illness or disability challenges the balance within the family system and probably disrupts all family members. Although there is a considerable body of research related to the problems of children with chronic conditions, less has been written about the impact of their physical impairments on family dynamics as the child moves through adolescence into adulthood.

Being a parent of a child with a chronic condition may have several emotional, physical and social consequences. As children mature and become more capable, most young people pursue advanced independence. In families with children with chronic conditions this road to independence can be extremely stressful, especially if a child does not become successfully independent when expected. Parents may express major concerns about the child’s physical prognosis and how it would affect future educational and work prospects, social interactions, emotional well-being and requirements for physical care. Parents of a chronically ill child, especially mothers, report high levels of anxiety and depression which in turn influences the parent–child interaction. For example, maternal depression is found to be associated with a more negative mother–child relationship and parental depressive symptoms were found to reduce concern for children’s feelings and interests. Parental psychosocial problems may also have an effect on the physical health of the chronically ill child. For instance, maternal depression was found to influence the child’s adherence to therapy, and asthmatic children of caregivers with a depressive or anxiety disorder had lower pulmonary function and asthma control. In a study in children with sickle cell disease, a direct association was shown of parenting stress with disease severity and healthcare utilization of their child.
Beside emotional impact, having a chronically ill child also influences family and social life as parents provide most of the daily care for their children. This daily care involves management of the illness or disability, which can be complex and is increasingly transferred from the hospital to the home (e.g., home dialysis, intravenous alimentation). Further care giving tasks comprise finding and coordinating appropriate care for their child, incorporating the care into family life, managing the consequences on siblings, and keeping the responsibilities of caring in balance with personal needs. In general, being a parent of a child with a chronic disease is a risk factor for experiencing negative consequences on HRQoL, employment and leisure activity time. In addition, for some parents responsibilities and the burden of care for the child will increase instead of decrease as the child ages and moves to adulthood. They contribute sizable material and emotional support through their children’s late twenties and into their early thirties.

Research on the psychological impact of having a brother or sister with a health condition has been sparse too. The sibling relationship is one of the most intense, influential, and lengthy relationships in our lifetime. Siblings have a powerful influence in shaping each other’s identity. When one sibling is seriously ill or disabled, the impact would be profound on the others. Healthy siblings also face multiple challenges in growing up with an impaired sibling, such as exposure to the physical and emotional pain of their brother’s or sister’s condition, fear, parental distress, and extended separation from the ill child and the parents because of hospitalizations. Studies have found siblings to be poorly adjusted to childhood chronic illness and disability, reporting increased behavioural and social problems, high levels of anxiety and restriction of family activities. In contrast, other researchers found siblings coping well by the experience of having an ill sister or brother or unclear findings have been reported. A meta-analysis of Sharpe and Rossiter found psychological functioning (i.e., depression, anxiety), peer activities, and cognitive development scores were lower for siblings of children with a chronic illness compared to controls. Illnesses that impact on the daily functioning of the sibling have the most profound impact on their wellbeing. Also, the awareness that they might have to take care for their brother or sister when their parents are no longer capable to do so, could be experienced by the siblings as a serious burden.

In general, families are often overburdened in extending support to children with chronic conditions as they make their way through this extended process of becoming an adult. Health care providers should view the child, adolescent or young adult with a chronic condition in the context of his or her family. An awareness of the effect of living with childhood illness and disability on parents and siblings is essential to healthcare professionals to give the informa-
tion and support which they need and to match the level of risk to appropriate interventions \(^65\). Unfortunately, research has shown that it is hard to integrate approaches such as family-centred services and long-term care for the child, in health care services \(^93\). PROs can be used to screen for risk within the family. Such family screening tools are scarce in pediatric psychology. Recently, the Psychosocial Assessment Tool (PAT) is developed, which is a brief parent-report screening tool of psychosocial risk (e.g. financial resources, social support, stress reactions, child problems, and sibling problems) in families that cope with pediatric illness \(^94\). The PAT is described as a promising screening tool in families of children with cancer \(^95\), kidney transplantation \(^96\), inflammatory bowel disease \(^97\) and sickle cell disease \(^98\).

**The role of parents; overprotection and lowered expectations**

A growing body of evidence supports the association between parental/family functioning and child adjustment outcomes in childhood chronic illness \(^99, 100\). The achievement of independence is an important issue in the upbringing of all children, but in the case of a child with chronic condition it appears to play an extra important role. Parents of children with a childhood onset disease often use a planned approach in order to stimulate the independence of the child. They encourage and stimulate the child’s progress to the next level of development, one step at the time \(^36\). Some parents indulge their children since these children already have to deal with the challenges of their condition, other parents are very strict on their children to prepare them for a rough world \(^36\). In a study among parents of children with disability benefits, the ACTION-study, it was found that almost all parents use their own knowledge, experience and skills to compensate the limited knowledge, experience and skills of their children with disability benefits. Their help was sometimes successful in reaching the goals of their child. Also, the children of parents who attached more importance to independence and work, appeared to be more likely to have passed the psychosocial development milestones (including independence and social development) and to have paid work \(^36\). Causality cannot be proven as the direction of the relationship is not known and many other factors play probably an important role, such as the physical capabilities of the young adults. For example, if independence and work for the young adult is not realistic, it is likely that parents adjust their expectations and goals. Their attitude towards the child’s independence and work could be based on what parents deem feasible for the child \(^36\). On the other hand, parents may have unrealistic expectations of their child. Realistic expectations are helpful, too low expectations are not. The consequences of unrealistically lowered expectations are multiple and can cause low self-esteem, poor decision making abilities, and less personal control \(^55\).
Parents of young people with chronic physical illness are, on average, more overprotective than other parents possibly leading to adjustment problems in their child caused by limited autonomy development. Parents who overprotect the child with a disease or disability will continue to overprotect as the child enters adolescence and young adulthood and inadvertently promote dependence on others. Overprotection inhibits the child from developing the personal skills needed to cope with the extra challenge of the chronic condition. In addition, overprotective parents may avoid talking with their children about negative emotions related to the disease, such as anxiety for the course of the illness, sadness about victimization by peers, and uncertainty about the future.

The way parents deal with the condition of their child (illness cognitions) and their burden of care provide clues for early detection of emotional problems (anxiety and depression) in parents. The knowledge that the care for their children is for ever can be very stressful. The following risk factors for parental emotional problems emerged from the ACTION study: insufficient support from family, problems with their own health, insufficient acceptance of the condition of the child and the feeling that the child’s condition determines their lives. Positive feelings and acceptance of the condition reduced feelings of anxiety and depression. All parents report that it is very hard to support their children in a balanced and useful way and to take their own perspective into account as well. In sum, many parents are worried about the future of their child, and they may have difficulties balancing protection and realistic stimulation of their child. Lowered expectations and overprotection of the child with an impairment can result in a life time of underachievement and failure to reach their full potential. Effective parenting is characterized by providing useful support to their child, while avoiding unrealistic low expectations or overprotection. This is of utmost importance during adolescence and emerging adulthood; the period of trying out different possibilities in different aspects of life. However, finding this balance is already difficult for parents of healthy children, not to mention for parents of children with a chronic condition. Parents need support in these areas; how to effectuate optimal parenting of a child with a chronic condition? Although the available research evidence is far from conclusive, the reported impact of parent’s functioning on child adjustment does support the need to target parenting in interventions for youth with chronic conditions. Systematic attention to the well-being of the parents, their burden of care and the way they deal with the child’s condition is needed.

POLICY
The social security system of the Netherlands is based on social insurances and supplementary income support provisions. The main principle of the system is
that all members of society must be able to play an equally active role in society. The government states that social rights and duties are two sides of the same coin, which means that those who are capable to work must work. In recent years a paradigm change in Dutch vocational policy took place from ‘protection’ to ‘participation’. Paid work is now explicitly valued above income compensation. This is partially due to the increase in the total cost of social assistance, and because employment is seen as an important condition for the wellbeing of individuals and society.

Certain groups may need support in finding their place in the labour market. The Dutch government has a task to create conditions for an inclusive society in which young people with health problems or disabilities can participate in the labour market and in society in general. To stimulate employment, the government should base the policy and laws on the notion that impaired people must be enabled to participate. The policy and laws have a high symbolic value because it stands for welcome signals from society. However, the legislation for the group of young people with chronic conditions changed three times in the last seven years. During this period, the indications for benefits have gradually been redefined more strictly and access to support has been tightened. These mixed signals – assigning importance to participation in society along with reducing support for young people with health problems or disabilities at the same time – might indicate that our society does not know how to deal with a group of young people unable to participate in the work force in the common way.

These dual signals can be seen in the new legislation once again. The Participation Act will enter into force on 1 January 2015 (see appendix). One of the goals of the new Participation Act is to enhance participation in the labour market by people with a disability. However, from 2015 on, only disabled young persons who are fully and permanently incapacitated to work are eligible to the Wajong. The group of persons currently receiving Wajong benefit payments (everyone admitted before 1 January 2015) will be assessed on their ability to work. Persons receiving Wajong benefit payments who do not have the ability to work will keep their benefit payments of 75 percent of the statutory minimum wage (SMW). Persons receiving Wajong benefits with the ability to work will be entitled to another social security benefit which means a decrease in their income to 70 percent of the SMW as from 1 January 2018. Municipalities are given a central role in the implementation of the Participation Act. The municipalities will be responsible for the provision of benefits and reintegration of new young disabled persons with the ability to work, and for a sheltered employment scheme for those who cannot perform regular work. Although additional funds will be made available to assist this group in getting a job, finding competitive
employment and gaining financial independence may be very hard for the most part of young adults with chronic conditions since the decentralization is also expected to generate additional savings. The efforts on improving the likelihood of successful participation of young adults with health problems on the labour market are at odds with the goal of additional savings. Lobby organizations for the handicapped and large employers organizations are critical of the initiative and claim that it is doomed to fail because it will sideline several groups of handicapped people. Notwithstanding the positive, effective components in this regulation this amendment is considered as a hidden cutback by many.

Other countries struggle with the promotion of labour participation of young people with health complaints as well. 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). Despite the different initiatives, like 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.

**COOPERATION BETWEEN INSTITUTES**

Any debate about the consequences of the ‘pediatric success story’ must consider the impact on all different institutes involved in maximising independence and autonomy in youth growing up with chronic conditions. As the transition to adulthood evolves, so too must society’s institutions – like healthcare, schools, employers, the Employee Insurance Agency (UWV), regional and local authorities – and their mutual cooperation. The fact that young people and their families struggle with the new reality of a longer and more demanding pathway into emerging adulthood and adult life, indicates that existing institutions may need to change and new co-operations have to be arranged. The existing institutions are usually designed but also restricted within certain aspects of life, as addressed by health, education and social welfare. However, today’s effective support can only be addressed across systems with a shared long-time perspective. Close collaboration between agencies, a transdisciplinary approach of the professionals involved and the use of key workers can be helpful in meeting the often-changing complex needs of youth with chronic conditions, as well as the needs of their parents. Even if each of the organisations involved is committed to act holistically, due to their different core business, they will still miss certain aspects relevant for the life of the adolescent and young adult. For different institutions to collaborate, not only are political decisions required but also the finances for the co-ordination making sure that the provided services are less
fragmented or duplicated and therefore more efficient.

**IMPROVING WORK PARTICIPATION**

This study points out the need for early attention to the achievement of developmental milestones and the development of skills and attitudes that young adults with chronic conditions need for future employment. Therefore, caregivers, teachers and health care providers have to be aware of problems with achieving age-typical milestones and refer to psychosocial services if necessary. In addition, young people with impairments are entitled to more support regarding vocational participation before the age of 18 (when benefits can first be claimed). First, these youth need to be informed about what is possible and feasible for them in the labour market. Teachers and health care providers are required to pay more attention to reasonable prospects for education and work. They can help to formulate realistic goals and empowering the adolescent or young adult for participation despite their limitations. Second, youth with chronic conditions need to explore their vocational capabilities and interests. Young people with a childhood onset can be unfamiliar with their capabilities and interests. Youth with chronic health conditions typically have less involvement in household chores and work experiences than their peers during high school. Early experiences with different kind of tasks can help to identify preferences and impossibilities as well as needed adjustments in the workplace. Third, they need support to develop skills to find work. Some key challenges for young people with a chronic condition or disability include disclosing their condition to employers and asking for accommodations at work. Training programs, job search assistance and job placement could increase the likelihood of obtaining employment for young adults with chronic conditions. If these vocational preparatory efforts are not made, the child may not develop the skills, confidence and motivation to be effective in work environments. Health care providers, school supervisors, transition counsellors and employers should have knowledge about resources and vocational services available to young persons with chronic conditions or disabilities and their parents. SAVTI (Successful Academic and Vocational Transition Initiative) of the Pediatric Oncology Group of Ontario (POGO) and Emma@work (job mediation for youth with a somatic disease, see appendix) of different children’s hospitals in the Netherlands are examples of valuable programs.

On another level, employers play an important role in improving job availability, job retention and re-integration for young people with disability benefits because of chronic health problems. It are the employers who can create real work opportunities. Employers should be aware that in today’s world with adaptive equipment and high technology electronic support systems, per-
sons with physical limitations can be effective workers in many environments. In addition, it is important that employers realize that the motivated and dedicated attitude of employees with physical impairments can have positive effects on the attitudes and commitment of co-workers as well as on the productivity. However, employers often have misplaced concerns about possible problems and costs of employees with physical impairments and fail to recognize the potential benefits. Possibly the most impeding factor is the misplaced belief that a person with an illness or disability is not a capable person. This stigmatization has prejudiced and restricted the vocational opportunities that are available to young persons with a chronic condition and can become a self-fulfilling prophesy. This is especially difficult in the economic current climate. There is evidence of discrimination against individuals with chronic illness and disability when applying for a job and in the workplace in general. Despite governmental incentives, activation policies have not yet proven to be effective in improving the employment prospects to people on disability benefits in the Netherlands. This shows that the social and occupational integration of chronically ill or disabled young people into society can never be enforced by incentives and regulations alone. Real integration ultimately depends on attitudes, inspired by human values of solidarity. Employment of youth with chronic impairments can bring — next to financial benefits as a result of schemes from the government — enthusiasm in the company and a positive image. Clearly, the economic situation is influencing the work participation of young adults too. Although youth unemployment in the Netherlands is relatively low from a European perspective, the youth unemployment rate has risen in the Netherlands as well. In the Netherlands, the unemployment rate of young adults in general (15-25 years) has risen from 9.3% in 2008 to 15.5% in 2013 (www.cbs.nl). Young adults with chronic conditions need protection and support to prevent exclusion in this tight labour market. Therefore, it is of utmost importance that employers, municipalities and the government provide suitable employment for young adults with chronic conditions to give them a rightful place in society.
KEYMESSAGES

• Growing up with a chronic illness and/or disabilities in childhood and adolescence has consequences for the transition to adulthood and beyond.
• Young adults with disability benefits with a chronic condition demonstrate delayed developmental trajectories across the transition to adolescence and adulthood. It is important to pay continuous attention to their developmental trajectory and emotional well-being.
• More consistent, early and rigorous monitoring of psychosocial outcomes in a lifespan perspective is needed.
• Health care providers’ awareness of the effect of childhood illness and disability on the whole family is essential.
• Pediatric and adult health care professionals need an optimal blend of knowledge, skill, attitudes, and experience in the medical and social issues of persons growing up with a childhood condition.
• The treatment and support must focus on meaningful and satisfying participation in society.
• It is important to stimulate young people with disabilities to be active in work. Preparation for employment at an early age is warranted.
• Achieving linkages between the organisations of health care, education, vocational community and social services is recommended.
• Our society needs to ensure that adequate resources and support are made available to all youths with chronic conditions and their families to maximize social participation.
REFERENCE LIST


08. Verhoof E, Maurice-Stam H, Grootenhuis M, Heymans H. EMWAjong study: growing up into a Wajong benefit. 2010. Amsterdam, Psychosocial Department, Emma Children’s Hospital AMC.


36. Verhoof E, Maurice-Stam H, Grootenhuis M. ACTION study. 2012. Amsterdam, Psychosocial Department, Emma Children’s Hospital AMC.


