

Transition to adulthood: validation of the Rotterdam Transition Profile for young adults with cerebral palsy and normal intelligence

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The aim of this study was to investigate the validity of the Rotterdam Transition Profile (RTP) to describe the transition process from childhood to adulthood in young adults with cerebral palsy (CP). Participants were recruited from rehabilitation centres and hospital departments of rehabilitation. In total, 81 young adults (47 males, 34 females) with CP and normal intelligence participated (mean age 20y 5mo [SD 1y 4mo] range 18–22y; 95% spastic CP, 48% hemiplegia, 38% diplegia, 14% quadriplegia; 78% Gross Motor Function Classification System Level I, 83% Manual Ability Classification System Level I). The RTP and the Assessment of Life Habits questionnaire are used to measure transition and functioning in daily activities and participation. Almost all participants were in the transition process or had reached an independent adult lifestyle (ranging from 60–100%, housing 42%). Compared with able-bodied peers, young adults with CP lagged behind in their development in housing (25 vs 36%; $p < 0.05$), employment (33 vs 49%; $p < 0.05$), and intimate relationships (37 vs 76%; $p < 0.01$). Associations were found between the phase of transition and age, parents' level of education, gross motor functioning, manual ability, level of education, and level of functioning in daily activities and participation. The RTP is a valid tool to gain more insight into the transition process, at the individual as well as at group level.

Adolescence is a period of biological, social, and emotional changes. In this period, adolescents consolidate their identity, achieve independence from parents, establish adult relationships outside the family, and find a vocation.^{1–6} For young people with disabilities the transition period is one of particular difficulty as they may be disadvantaged by their impairments, the extra health maintenance skills they need to acquire, lack of experience in activities and participation, social isolation, or by other environmental, family, and personal factors.^{3,6–12} Failure to make a successful transition to adulthood may result in unnecessary lifelong dependency, unemployment, lack of achievement, and poor quality of life.^{4,7,10}

Transition to adulthood is a complex process which extends over several years.³ The process encompasses different developmental stages. At first the adolescent is dependent on adults, usually parents and teachers. Later, the young adults orientate towards a more independent way of life and finally become independent autonomous adults who manage their own life. The transition process involves different domains of participation, e.g. employment, housing, leisure activities, financial situation, interpersonal relations, and sexuality. The transition does not necessarily follow the same pace in each domain of participation. For example, young adults can be financially independent but still live

with their parents. In the literature, information is lacking on which aspects of participation and in which phases of transition young persons with cerebral palsy (CP) are successful or may encounter difficulties.

During childhood, children with CP receive intensive and structured rehabilitation treatment and psychosocial support; however, after discharge from paediatric rehabilitation or leaving secondary school, the continuity of care is often disturbed. In general, during the transition process there is no structured rehabilitation treatment whereas major changes take place, particularly during that period, that may (temporarily) disrupt normal life and need both personal and environmental adjustments.

In the current paper we will describe the transition process in more detail using the Rotterdam Transition Profile (RTP), classifying a person's developmental stage for various domains of participation and health care. This study aimed to investigate the construct validity of the RTP by comparing the transition of adolescents and young people with CP with able-bodied peers; assessing associations of transition with participant characteristics and functioning in activities and participation; and studying the transition over time.

METHOD

Development of the Rotterdam Transition Profile

We developed the RTP as a tool to summarize the transition process of adolescents and young adults with CP. The profile may be used in research as well as in clinical practice to monitor adolescents and young adults during their transition to adulthood. According to theories of developmental psychology¹³⁻¹⁵ and knowledge on transition to adulthood, three developmental phases in transition are distinguished. First the adolescent is dependent on adults, usually parents and teachers (phase 1). Later, the young adult orientates towards a more independent way of life (phase 2), and finally becomes (more-or-less) independent, managing his or her life autonomously (phase 3).

Several major life events take place during the process of transition^{4-6,11,16} (i.e. finishing school and starting a job, leaving home, and living on your own). These events refer to domains of participation that are distinguished in the International Classification of Functioning, Disability and Health¹⁷ and in measuring instruments on participation and autonomy such as the Life Habits questionnaire (LIFE-H)¹⁸ and the Impact on Participation and Autonomy questionnaire.¹⁹ The RTP addresses six domains of participation: Finances, Education and employment, Housing, Intimate relationships, Transportation and Leisure activities, and three healthcare domains: Rehabilitation Services, Services &

Aids, Care demands (see Appendix Ia). These domains were chosen following discussions with rehabilitation professionals in the Transition Research Group South West Netherlands.

Study design

This investigation is part of the Transition Research Group South West Netherlands study, a study into the course and determinants of functioning of adolescents and young adults with CP and normal intelligence.²⁰ Every 2 years, participants are invited for extensive assessments, including a functional evaluation and a semi-structured interview on activities, participation, and transition issues. The results presented in this paper are mainly based on the 2-year follow-up assessments (T₁).

Participants

Participants were recruited from eight participating rehabilitation centres and rehabilitation departments in the South West Netherlands. The inclusion criteria were: (1) diagnosis of CP; (2) born in the years 1982 to 1986; and (3) normal intelligence (roughly corresponding with an IQ above 70, excluding participants who attended schools for those with learning disabilities*). CP is defined as a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain.²¹ Exclusion criteria were (1) additional diagnosis with lasting effects on motor functioning and (2) insufficient knowledge of the Dutch language.

Of a population of 437 adolescents and young adults with CP, 35% was excluded because of learning disabilities and 18% was lost due to incorrect addresses. An information letter about the study was sent to 184 potential participants.

At baseline (T₀), 103 adolescents and young adults participated, a response rate of 56%. No significant difference was found between responders and non-responders with respect to sex, age, type of CP, and CP limb distribution.²⁰ At 2-year follow-up (T₁) participants were aged between 18 and 22 years old. There was a drop-out of 16% due to loss of interest (*n*=9), too busy (*n*=5), and moved to another country (*n*=2). The current paper presents results of all participants for whom data on transition are available at 2-year follow-up and at baseline (*n*=81). Compared with baseline characteristics of the study population, drop out was not selective regarding age, sex, gross motor function, limb distribution, and educational level.

*North American usage: mental retardation

Participants gave verbal and written consent to participate. The Medical Ethics Committee of Erasmus MC University Medical Centre Rotterdam approved the study.

Measurements

Demographic and clinical characteristics

The following characteristics were recorded: sex, age, type of CP, limb distribution of CP, gross motor function, manual ability, level of education, and parents' level of education.

Gross motor functioning was classified with the Gross Motor Function Classification System (GMFCS).²² The GMFCS is a five-level classification system addressing severity of gross motor limitations.^{22,23} Manual ability was classified with the Manual Ability Classification System (MACS), a system to classify how children with CP use their hands when handling objects in daily activities, and is also valid in young adults with CP.^{24,25}

Three levels of education were distinguished; (low) pre-vocational practical education or lower; (medium) pre-vocational theoretical education and upper secondary vocational education; and (high) secondary non-vocational education, higher education, and university.

Participation and transition

Functioning in daily activities and participation was measured with the Life Habits questionnaire – shortened version (LIFE-H 3.0) addressing social participation of people with disabilities.¹⁸ The LIFE-H was included in a large semi-structured interview. The short version, the LIFE-H 3.0 is composed of 69 life habits divided into 12 categories. These categories (number of items) are: nutrition (three), fitness (three), personal care (seven), communication (seven), housing (eight), mobility (five), responsibilities (six), interpersonal relationships (seven), community life (seven), education (three), employment (seven), and recreation (six). The first six categories refer to daily activities while the other six are associated with social roles.

The LIFE-H performance score is based on the level of difficulty and assistance required to carry out the activities or roles. The performance score ranges from 'not accomplished' (0) to 'accomplished without difficulty' (9). Mean scores were calculated for all categories, two subdomains, and the LIFE-H total score. Mean scores below 8 indicate difficulty in performance. Good reliability was found for different groups of adult patients.^{26,27}

Transition to adulthood was scored using the RTP which was filled out by the researcher in the last part of the interview. The participation domains 'transportation' and 'leisure activities' and the healthcare domains 'services &

aids' and 'care demands' were assessed only at follow-up as at baseline these domains were not yet included in the transition profile.

Statistical analysis

Descriptive statistics were used to present participant characteristics of the study population, their level of functioning, and the distribution on the RTP. Because many participants did not need special health care services or special aids ($n=34$), this domain was excluded from further analyses.

In the absence of a criterion standard or other instruments to assess transition to adulthood, the construct validity of the RTP was investigated. We focused on three aspects: comparison with able-bodied people of the same age; associations with participant characteristics and functioning in activities and participation; and change over time. We tested the expectations that: (1) young adults with CP will attain independence later in life than able-bodied people of the same age; (2) the phase of transition is associated with age and, to some extent, to gross motor functioning, manual ability, level of education, and difficulties encountered in activities and participation; and (3) in a period of 2 years, young adults with CP will become more independent in the domains of the RTP.

We compared participation of young adults with CP with age-appropriate reference values of the Dutch population on work and education, housing (Statistics Netherlands),²⁸ and intimate relationships (Dutch expert centre on sexuality, Rutgers Nisso Group/SOAids)²⁹ by means of binomial tests.

The correlation between age and phase of transition was assessed with a Spearman's correlation coefficient. For other characteristics, partial rank correlations were used correcting for age, since the developmental phases of the transition profile are partly age related. The bootstrap method was used to study the significance of the partial rank correlations.

To assess change over time at group level and individual level we compared results on the RTP at follow-up (range 18–22y) with baseline (range 16–20y). At group level, the increase or decrease of the percentage of persons in a specific phase and domain of transition was assessed by means of a marginal homogeneity test, which is an extension of the McNemar test. Regarding change in individual persons, the term 'deterioration' indicates that at 2-year follow-up, a person is in a lower phase of transition compared with baseline. We used the term deterioration because, in general, typical development would follow the phases from 1 to 3.

Analyses were carried out using SPSS for Windows, version 12.0 and R 2.5.0.

RESULTS

Characteristics and functioning of the study population

Table I shows characteristics of the 81 participants. There were more male than female participants in the study, and there were relatively few persons in the youngest age group. The majority of the participants' parents had a medium or high level of education. More than 75% was classified at GMFCS Level I and MACS Level I. As a result of the inclusion criteria, none of the participants had a learning disability; 74% of them followed secondary general, upper vocational, or higher education.

About 20% of the participants had difficulty in performance of daily activities and social participation (LIFE-H mean score <8). Most difficulties were encountered in mobility (31%), personal care (21%), and employment (28%).

Transition to adulthood

Table II presents the distributions on the transition profile at the age of 18 to 22 years (T_1). Almost all the participants were in the transition process or had reached the independent adult phase on the participation domains, except for housing.

Table 1: Characteristics of the study population at 2-year follow-up ($n = 81$)

	<i>n</i>	%		<i>n</i>	%
Sex			Type of CP		
Male	47	58	Spastic	77	95
Female	34	42	Ataxic	1	1
			Dyskinetic	1	1
			Mixed	2	3
Age, y			CP limb distribution		
18	5	6	Hemiplegia	39	48
19	22	27	Diplegia	31	38
20	12	15	Quadriplegia	11	14
21	23	28			
22	19	24			
Mean, SD	20.4	1.3			
Participant of education			Parents' level of education ^a		
Low	21	26	Low	10	12
Medium	32	39	Medium	36	44
High	28	35	High	29	36
GMFCS			MACS ¹		
Level I	63	78	Level I	65	83
Level II	7	9	Level II	7	9
Level III	5	6	Level III	4	5
Level IV	5	6	Level IV	1	1
Level V	1	1	Level V	1	1
LIFE-H Daily activities			LIFE-H Social Roles		
	Difficulty in performance ^b			Difficulty in performance ^b	
Communication	8	10	Relationships ^c	7	9
Mobility	25	31	Education ^c	6	11
Personal care	17	21	Employment ^c	13	28
Fitness ^c	7	11	Responsibility	10	12
Housing ^c	7	9	Community	14	17
Nutrition ^c	12	19	Leisure ^c	14	18
Daily activities	17	21	Social roles	16	20

^aMissing data on parents' level of education ($n = 6$) and Manual Ability Classification System (MACS; $n = 3$). ^bPercentage of participants with difficulty in performance; Assessment of Life Habits (LIFE-H) mean score <8. ^cThese domains (or >50% of the items within these domains) were not applicable for all participants: in these cases domain scores could not be calculated. Fitness ($n = 19$), Housing ($n = 2$), Nutrition ($n = 16$), Relationships ($n = 4$), Education ($n = 27$), Employment ($n = 35$), Leisure ($n = 4$). GMFCS, Gross Motor Function Classification System; MACS, Manual Ability Classification System.

Table II: Distribution on the Rotterdam Transition Profile at 2-year follow-up

Transition	n	2y follow-up (range 18–22y)		
		Phase 1,%	Phase 2,%	Phase 3,%
<i>Participation</i>				
Finances	77	0	52	48
Employment	81	9	58	33
Housing	81	58	17	25
Intimate relationship	81	40	24	37
Transportation	81	6	4	90
Leisure	78	9	7	80
<i>Health care</i>				
Rehabilitation	81	14	54	32
Services & Aids	34	18	50	32
Care demands	81	4	32	64

About 25% of the participants lived on their own, which is significantly less than able-bodied Dutch people of the same age (36%; $p < 0.05$; reference age 18–22y).²⁸ With respect to intimate relationships we see a comparable pattern. Less than 40% had an intimate relationship with intercourse (phase 3), a low percentage compared with Dutch able-bodied peers (76%; $p < 0.01$; reference age 18–21y).²⁹ Furthermore, the results show that 90% of the participants organized transportation independently (i.e. driving a car, calling a taxi, or using public transportation) and 80% went out in the evening to a party, a concert, or the cinema. Regarding employment, many participants were in transition, orientating on a job (58%) and 33% had finished their training. In fact, 23% of the young adults with CP had a job, a low percentage compared with Dutch able-bodied peers (49%; $p < 0.05$; reference age 18–24y).²⁸ About 50% were independent regarding finances (i.e. disability benefits or paid job), the others were partially dependent on their parents.

Regarding transition in health care, we found that about half of the total group did not visit a rehabilitation physician in the previous year and one-third visited a rehabilitation physician in adult care. A comparable pattern was found for applying for services & aids, which was applicable for only 34 participants. The majority of the participants were able to formulate their care demands themselves (64%) or together with their parents (32%).

Associations

Association between transition and participant characteristics

Except for sex, participant characteristics were related to the transition profile at the age of 18 to 22 years (T_1 ;

Table III). All associations were corrected for age. The association between age and transition was expected from the developmental aspect of the transition profile. At baseline this association was even more obvious (r_s between 0.33 and 0.68).

Participants whose parents had a higher level of education were financially more dependent on their parents. A high level of motor functioning was related to financial dependence and to independence in transportation. In addition, participants with a high level of motor functioning were more often independent with respect to leisure activities (e.g. going out in the evenings to a party, concert, or the cinema). A high level of manual ability was related to financial dependence and following general education (as opposed to having a job or following job training). It was also related to a more adult phase of intimate relationships and independence in transportation and leisure activities. Participants with a higher educational level were more dependent with respect to finances and a large part was still following education.

Regarding health care, participants with a higher level of motor functioning (gross motor and manual) and higher level of education were more likely to formulate their care demands independently. Whether participants consulted a paediatric or adult rehabilitation physician did not correlate to participant characteristics.

Association between transition and level of functioning in activities and participation

The last column of Table III presents data on the associations between transition and level of functioning in activities and participation (total LIFE-H score). Young adults who did not yet reach phase 3 in transportation, leisure activities, and intimate relationships ($n=13$, $n=8$, and $n=53$ respectively), experienced more difficulties in

Table III: Associations between subject characteristics and transition phases of the Rotterdam Transition Profile ($n=81$)

Transition	Age ^b	Correlations corrected for age ^a					
		Sex	Parents' education	GMFCS ^c	MACS ^c	Education	LIFE-H
<i>Participation</i>							
Finances	0.05	0.05	-0.26 ^d	-0.32 ^e	-0.43 ^e	-0.46 ^e	-0.56 ^e
Employment	0.34 ^e	0.07	-0.18	0.01	-0.20 ^d	-0.44 ^e	-0.22
Housing	0.08	0.09	0.13	0.00	-0.09	0.07	0.01
Intimate relationship	0.37 ^e	0.03	0.08	0.16	0.35 ^e	0.05	0.27 ^d
Transportation	0.35 ^e	0.02	0.11	0.30 ^d	0.39 ^e	0.21	0.40 ^e
Leisure	0.13	0.09	0.02	0.33 ^e	0.40 ^e	0.13	0.40 ^e
<i>Health care</i>							
Rehabilitation	0.15	0.03	-0.05	0.03	-0.07	-0.21	-0.13
Care demands	0.05	0.06	0.17	0.24 [*]	0.23 ^d	0.25 ^d	0.44 ^e

^aPartial rank correlations, correction for age; ^bSpearman's correlations. ^cGross Motor Function Classification System (GMFCS) and Manual Ability Classification System (MACS) are recoded (higher score, better ability). ^d $p \leq 0.05$; ^e $p \leq 0.01$. LIFE-H, Assessment of Life Habits.

activities and participation compared with young adults in phase 3. Also in the specific LIFE-H domains of transportation and leisure they encountered more difficulties (partial correlation between 0.28; $p < 0.05$ and 0.40; $p < 0.01$; data not shown).

For transition in finances and housing, participants who reached phase 3 experienced more difficulties in functioning, also in the specific LIFE-H domain of using money and managing their finances (partial correlation -0.37; $p < 0.01$).

With respect to transition in health care, participants with a higher level of functioning in activities and participation were more likely to formulate their care demands independently. For visiting a paediatric or adult rehabilitation department no association was found.

Course of transition over time

During a period of 2 years, participants became more independent on all domains of transition (marginal homogeneity test; $p < 0.01$). Figure 1 shows the percentage of participants in each phase of transition at baseline (T_0) and at 2 years follow-up (T_1). Over this period the percentage of participants in phase 1 diminished and in phase 3 increased substantially.

On an individual level, about 32 to 40% of the participants improved over time on the domains of the RTP, whereas about 56 to 64% did not. Seven participants deteriorated on one or two transition domains. Main reasons for this were changing from a vocational education to general education and moving back to the parental home.

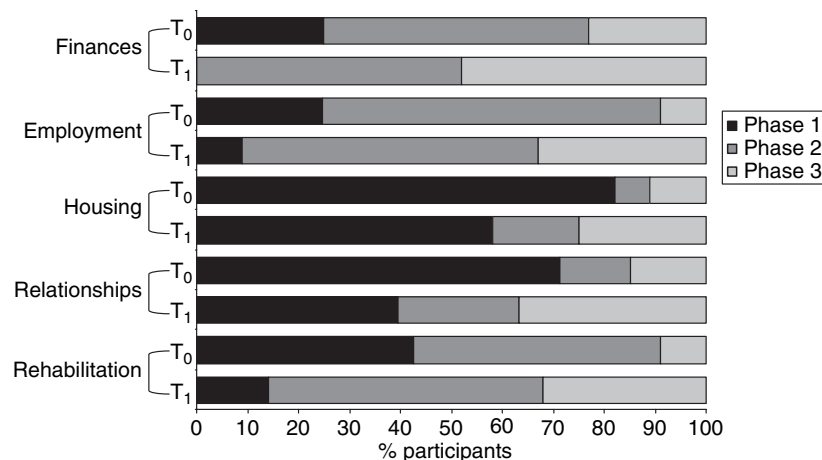


Figure 1: Change on the Rotterdam Transition Profile over a 2-year period for a cohort of young adults with CP and normal intelligence.

DISCUSSION

The results of this study provided support for the construct validity of the RTP to classify transition in young adults with CP, on both individual and group level. We compared transition of youth with CP to Dutch able-bodied people of the same age, related transition to participant characteristics and social participation (LIFE-H), and assessed change in transition over time. For these three aspects results were in accordance with the expectations tested.

First, the participants in this study were 18 to 22 years of age, and almost all were in the process of transition or had reached an independent adult lifestyle in several domains of participation. As expected, compared with Dutch able-bodied peers they lagged behind in their transition to adulthood. It should be noted that the RTP is based on the Dutch situation and might be influenced, for example, by Dutch values on independent living, legislation regarding benefits, and education or environmental factors, such as good public transportation.

Secondly, the current study showed that the transition profile – addressing a developmental process – was correlated to age. In addition, the transition profile was correlated to motor functioning (GMFCS, MACS), level of education, and level of functioning in activities and participation. It should be noticed that the strength of these associations was only moderately or poor, which might be explained by the assumed influence of other factors on the transition process.

The negative associations found between level of education and the transition in finances and employment may be explained from the fact that a higher level of education takes additional years. Thus, people following higher education can be expected to reach independence in employment at an older age and they might be financially dependent on their parents for a longer period. Besides the participant's level of education, transition in finances was also negatively related to the parents' level of education, motor functioning, and functioning in activities and participation. These results might be influenced by the Dutch system of additional benefits for (young) people with disabilities that makes them financially independent at the age of 18 years. Furthermore, participants who were functioning more independently (phase 3) with respect to leisure activities and transportation had a higher level of motor functioning and encountered less difficulties in activities and participation compared with participants in phase 1 or 2.

With respect to the transition in health care, the majority of the participants formulated their care demands themselves and this was related to a high level of functioning. Half of the young adults with CP did not visit a rehabilita-

tion physician in the previous year. Remarkably, the use of paediatric or adult rehabilitation services was not related to participant characteristics or difficulty in activities and participation.

Third, addressing change over time, the results showed different mechanisms at work during the transition process. Regarding the process of ageing, as can be expected, an older age coincided with a higher transition phase. Second, a low level of functioning was related to a slower transition or might lead to an unsuccessful transition. Evidence for the second mechanism was our finding that young adults with CP lagged behind their able-bodied peers, and that a high level of functioning was related to a more independent adult lifestyle in leisure activities and transportation. On the other hand, in a higher transition phase the expectations from the environment are also higher and therefore we assumed that young adults would encounter more difficulties in transition phase 3. This mechanism can be indicated as 'growing into a deficit'. An example of this third mechanism is that participants living on their own encountered more difficulties in housing activities. These results might imply that the RTP can be used to formulate adequate treatment goals and to improve treatment of young adults with CP.

It should be emphasized that this study focused on young adults with CP without learning disabilities since we expect them to be capable of living an independent adult life. Therefore, the results of this study may only be generalized to the population of young adults with CP of normal intelligence. We performed some additional checks on whether the present cohort is truly representative for this group. First, in the Netherlands it is standard clinical practice to refer all children diagnosed with CP to paediatric rehabilitation care. Since we recruited participants by means of the patients' record systems of both paediatric and adult departments of rehabilitation centres and hospitals in the region, we had access to young adults with CP who were still using health care as well as those who only visited the rehabilitation centre or hospital in their childhood. Second, the distribution of GMFCS levels in our cohort was rather comparable to the normal intelligent subgroup of two Dutch population-based studies among young adults with CP³⁰ and school-aged children.³¹ Respectively, 86 and 73% of these study populations were classified in GMFCS Levels I and II.^{30,31} On the other hand, it should be noted that the parents of the participants in this study were relatively highly educated compared with parents of children with CP in the Study of Participation of Children with Cerebral Palsy Living in Europe in the European (SPARCLE)³² This might either be related to the exclusion of young people learning disabilities or might reflect the possible mechanism that higher educated par-

ents encouraged their child more strongly to participate in our study. Either way, in a previous publication we showed that the parents' level of education was not related to functioning in activities and participation of youth with CP.²⁰ These checks supported the generalizability of the results to the population of young adults with CP without learning disabilities.

CONCLUSION

The RTP seems a valid tool to gain insight into the transition process, on both individual and group level. We found that young adults with CP of normal intelligence showed a delayed development in independent housing, intimate relationships, and employment. The results indicated both facilitating and limiting factors at work to reach independent life. Overall, over a period of 2 years, young adults with CP became more independent in all domains of participation.

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Appendix Ia: Descriptions of the phases and domains of the Rotterdam Transition Profile

	Phase 1 (Childhood)	Phase 2 (Transition)	Phase 3 (Adulthood)
<i>Participation</i>			
Finances	Pocket money	Job on the side	Benefits
Education and Employment	Clothing allowance	Student grants	Job income
Housing	General education	Vocational training	Paid job
Intimate relationships	Living with parents	Work placement	Volunteer work
Transportation	No partner	Seeking housing	Living independently
Leisure (social activities)	No sexual activity	Domestic training	
Health care	Parents' or carers' transport	Dating, beginning of sexual activity	Sexual relationship with intercourse
Rehabilitation Services	Leisure activities at home	Parents' or carers' arrange transportation	Young adult arranges transportation
Services & Aids	Child rehabilitation	Leisure activities outside the home	Going out in the evening
Care demands	Parents apply for services & aids	No rehabilitation visits in the past year	Rehabilitation, adult department
	Parents formulate care demands	Young adult learns the procedures	Young adult applies for services & aids
		Parents & young adult formulate care demands together	Young adult formulates care demands

Appendix Ib: Case – 'Daniel'

'Daniel' is a 21-year-old young adult with hemiplegia, functioning at Gross Motor Function Classification System Level II and is activities of daily living-independent. He has a disability pension and is financially independent. He is undergoing a job training in computer technology, lives with his parents, and is responsible for some house-keeping chores. Daniel has a girlfriend for several years and they have an adult intimate relationship with intercourse. With his girlfriend (and friends) he goes out during daytime as well as in the evenings. Two years ago, when he was 19-years-old, he was not helping in the household and he was not going out in the evenings. Daniel did not visit a rehabilitation physician for several years.

Participation Domains	Transition phases		
	Phase 1	Phase 2	Phase 3
Finances			X
Employment		X	
Housing	T ₀ →	T ₁	
Intimate relationships			X
Leisure activities		T ₀ →	T ₁
Rehabilitation		X	



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