Review

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The use of the Rotterdam Transition Profile: 10 years in review

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Abstract: The aim of this literature review was to describe the use and utility of the Rotterdam Transition Profile (RTP), as we near the tenth year since its publication in 2008. It is a tool to summarize a youth's transition process to adulthood by classifying various domains of participation and health care into developmental stages. This review provided a comprehensive synthesis of available knowledge on the RTP by summarizing published and grey literature. Using search terms related to transition, social participation, and questionnaire, a systematic search was conducted for literature up to November 2017 in MEDLINE and Embase databases, and was supplemented with a hand-search using Google Scholar and a general internet search using Google Search. Inclusion criteria were specified to determine the papers selected for review, yielding fifty-five materials for detailed review. Combined analysis of published and grey literature identified nine papers that used some form of the RTP as a measure, 18 materials that cited the RTP or its domains but did not employ it as a measure, and twenty-eight materials that cited the original RTP development and validation paper for information not directly related to the RTP. The literature demonstrated that the RTP seems to be a useful tool to describe and monitor the transition process of adolescents and young adults, in both research and clinical settings. While it has been used with youth of 14–31 years of age across genders and health conditions, more evidence is needed to demonstrate its psychometric properties beyond construct validity in young adults with cerebral palsy.

Keywords: autonomy; independence; measure; participation; youth.

Introduction

The rapid advancements in medical technology in the last decades have enabled most youth with chronic conditions or disabilities to reach adulthood; thus, transition to adult health care is a highly relevant issue [1–3]. For young people with chronic and developmental conditions, the transition may be especially challenging in various life domains, as they progress into adulthood [4–6]. There is often a focus on the difficulties of the clinical transition; pediatric services usually end when an individual reaches the age of 18 and has very different expectations of youth compared to adult systems, which may lead to stress [6, 7]. The change may be drastic from the family centered, developmentally focused, multidisciplinary pediatric culture to the collaborative adult medical care, which focuses on patient autonomy, diseases, and employment issues but overlooks growth, development, and family concerns [7, 8]. A series of focus groups with a wide range of adolescents and young adults, family members, and health care providers with experience in transition deemed health care transition as a complex and dynamic process that is impacted by numerous factors, some of which promote transition, and others hinder the process [1].

While the clinical transfer to adult-oriented services is a concern, the transition process is also marked by social changes that occur outside of health care [9, 10]. Adolescence is a period of tremendous transition, regardless of one's state of health. During adolescence, one may strengthen one's own identity, achieve independence from parents, begin relationships outside of the family, and find a vocation [9, 11]. For example, many young adults finish school, move away from home, start a job, or pursue serious intimate relationships. However, youth with disabilities may encounter difficulties transitioning due to impairments, forced dependence, additional skills one needs to acquire for health maintenance, insufficient experience in activities, social isolation, as well as other personal and environmental factors [12–14]. Unsuccessful transition to adulthood may lead to unemployment, lifelong dependency, and poor quality of life [12, 15].

Transition profiles may be used to both benchmark and measure change throughout a participant's transition.

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Tools for assessment of youth's self-management before, during, and after transition to adulthood are necessary for determining where adolescents and young adults are on their transition journey and providing the appropriate interventions to assist them in improving social participation outcomes. The Rotterdam Transition Profile (RTP) is a tool to describe the transition process of adolescents and young adults with cerebral palsy (CP) [12]. The RTP classifies an individual's developmental stage for various domains of participation and health care, and has been utilized in several studies as a transition measure for young populations with varying chronic and developmental disabilities [12, 16–23].

As we near the tenth year since the publication of this tool in 2008, there is a need to identify and synthesize the existing knowledge regarding the use and utility of the RTP in assessing adolescents and young adults' transition process across a variety of diagnoses and research settings. A review will provide a snapshot of the use and utility of the tool and inform the academic audience and other end-users where this tool has been applied and in what contexts, which would, in turn, inform future transition research and assist in knowledge translation. In this paper, we aim to provide a comprehensive synthesis of the use of the RTP specifically across studies with different patient populations, purposes, and key findings.

Methods

Description of the RTP

The RTP was developed by Donkervoort et al. [12] in the Netherlands as a tool to summarize the transition process of adolescents and young adults with CP. The RTP classifies an individual's developmental stage for various domains of participation; finances, housing, education and employment, intimate relationships, leisure activities, and transportation, and the health service domains; service and aids, rehabilitation services, and care needs. Another version of the RTP includes a seventh participation domain of sexuality, derived from the intimate relationships domain [17]. Scores in each domain can be categorized into one of three different phases: dependent on adults (phase 1), experimenting and orienting with the future (phase 2), and independent and autonomous life (phase 3). The RTP was designed for use in adolescents and young adults in research and clinical settings, and has been validated for the classification of transition phases of young adults with CP of normal intelligence and without learning disabilities [12].

Data collection

We considered two sources of evidence: (a) published and peer-reviewed literature and (b) grey literature. The search of published literature included a systematic search aimed at identifying studies that described, employed, or cited the RTP, and a hand-search to examine all papers that cited the original study by Donkervoort et al. [12] on the development and validation of the RTP (Figure 1). As the databases do not search the full texts of papers, it was difficult to restrict the search to identifying only studies that mention the RTP. A search strategy was thus developed with the assistance of a health sciences research librarian, combining three series of search terms related to: transition to adulthood; social participation and self-management; questionnaire. The systematic search was conducted in November 2017 by SZJ. Papers were only included if they (a) contained at least one mention of the RTP, (b) were available in English, and (c) were published in or after 2008, which is the year the original RTP study was first published [12]. No restriction pertaining specific conditions or disabilities was placed, as a preliminary literature search yielded results with study samples of numerous different conditions. Database searching using MEDLINE and Embase identified 222 unduplicated articles. Title and abstracts were screened by SZJ and rejected if the papers were unrelated to transition to adulthood of youth with any chronic, developmental, or medical condition. The full text was obtained for 148 articles, of which five met the inclusion criteria. The hand-search was conducted in November 2017 by SZJ using Google Scholar, yielding thirty-three unduplicated articles.

Grey literature was searched in November 2017 using MEDLINE and Embase with the identical search strategy and inclusion criteria as that used for published articles, yielding one conference abstract. Hand-searching using Google Scholar identified five materials: one book, three graduate theses, and one evidence report. Additional internet searches were conducted in Google Search for any relevant unpublished data in English, with no time or geographical restrictions applied. Eleven materials were identified, including graduate theses, conference presentation slides, and other reports.

Results

Combined analysis of peer-reviewed and grey literature resulted in the identification of three main categories. These categories were (a) papers that used some form of

Figure 1: Flowchart of search procedure.

the RTP as a measure, (b) materials that cited the RTP or its domains but did not employ it as a measure, and (c) materials that cited the original RTP development and validation paper by Donkervoort et al. for information not directly related to the RTP.

Studies that used some form of the RTP as a measure

A total of eight published papers and one graduate thesis listed some form of the RTP as a measure in their study. One paper in this category (Colver et al. [16]) was excluded from further analysis as it served as a protocol for another study (Merrick et al. [21]) also included in this category. Two papers (Sattoe et al. [19, 23]) reported on the same dataset of young adults with chronic conditions but differed in their analysis, and was included in our analysis as two separate materials. These eight studies (Table 1) were

analyzed to identify common themes of study design and use of the RTP.

Study design

The overall design of the studies differed in terms of the type of study and the number, age, and health condition of participants. Three studies only utilized the RTP at baseline [17, 18, 21] and four studies were of a cross-sectional design [19, 20, 22, 23], while one study reported longitudinal data on the RTP with a 2 year follow-up time [12]. One study incorporated a comparison of RTP scores between the CP population and able-bodied peers of the same age using government statistics and expert opinion on employment, education, housing, and intimate relationships [12]. Similarly, another study extracted reference data from government statistics and a report on youth sexual health to compare the chronic conditions population

Table 1: Studies that employed a form of the Rotterdam Transition Profile (RTP) as a measure ($n = 8$).

Study	Design	Notes regarding the RTP's use	Participants characteristics at baseline			Findings regarding the RTP
			Number & diagnosis	Age	Gender	
Donkervoort et al. [12]	Longitudinal cohort study	RTP filled out by the researcher during semi-structured interview Transportation, leisure and the health care domains were assessed at 2 year follow-up but not at baseline	81 young adults with CP	Mean: 18.4 (SD = 1.3) Range: 16–20	Male: 47 (58%)	The RTP validated as a tool to more insight into the transition process Most participants with CP found to be in the process of transition or had reached an independent adult lifestyle in several domains, but lagged behind Dutch able-bodied peers A correlation found between the RTP and age Different mechanisms are at work during the transition process
Hilberink et al. [17]	Pre-post cohort study	7 participation domains; includes 'sexuality' as a separate domain Used the health care component, but did not describe the findings 0 follow-up time, as social participation only measured pre-intervention	14 adolescents and young adults from rehabilitation centers and schools for physically disabled adolescents (conditions include CP, SB and neuromuscular disease)	Mean: 19.9 (SD = 4.6) Range: 14–31	Male: 11 (79%)	Participants were relatively independent in finances and transportation, but had few intimate relationships School participants more experienced than rehabilitation participants in intimacy and sexuality experiences
Sattoe et al. [18]	Mixed methods study	7 participation domains; includes 'sexuality' as a separate domain Phases dichotomized; a score of 1 indicated full autonomy in participation No mention of health care component 0 follow up time for phase 2 (prospective), as social participation was only measured pre-intervention	56 young adults with ESRD Phase 1 (retrospective): 24 participants Phase 2 (prospective): 32 participants	Range of all participants: 16–25 Phase 1 (retrospective): Mean: 20.8 (SD = 3.2) Phase 2 (prospective): Mean: 19.1 (SD = 2.4)	Phase 1 (retrospective): Male: 8 (33%) Phase 2 (prospective): Male: 17 (53%)	Participants showed little autonomy in the areas of finances, employment, and living, while enjoying romantic relationships and socialization with peers

Table 1 (continued)

Study	Design	Notes regarding the RTP's use	Participants characteristics at baseline			Findings regarding the RTP
			Number & diagnosis	Age	Gender	
Sattoe et al. [19]	Survey (cross-sectional)	7 participation domains; includes 'sexuality' as a separate domain Phases dichotomized; a score of 1 indicated full autonomy in participation No mention of health care component	483 young adults with various chronic conditions	Mean: 20.6 (SD = 1.9) Range: 18–25	Male: 184 (38%)	Four distinctive patterns identified regarding autonomy in social participation More males in the group of slow developers compared with the others groups The level of social participation was positively associated with well-being High social participation was positively associated with self-efficacy and independence RTP domains did not significantly predict variance in health-related quality of life (HRQOL) Suggested that RTP to be more suitable for older individuals
Ingebrigtsen [20]	Cross-sectional study	7 participation domains; includes 'sexuality' as a separate domain Used health care component	57 adolescents with CP	Mean: 15.9 (SD = 1.0) Range: 15–17	Male: 30 (52%)	Young people with CP or ASD reported lower levels of independence in all domains except for education and employment than those with diabetes Participants mainly experienced limitations in education and employment, with some complications in transportation few limitations on other domains
Merrick et al. [21]	Longitudinal cohort study	Used health care component Baseline data reported only	374 young adults with ASD and additional mental health problems, CP, or diabetes	Mean: 16.2 (SD = 1.3) Range: 14–18	Male: 219 (59%)	Participants mainly experienced limitations in education and employment, with some complications in transportation few limitations on other domains
Lankhorst et al. [22]	Qualitative study (cross-sectional)	Semi-structured interviews were structured based on RTP domains Incorporated social interaction and friendship into the intimate relationships domain No mention of health care component	15 young adults with tULRD	Mean: 21.4 (SD = 2.2) Range: 18–25	Male: 5 (33%)	No significant associations found between RTP data and indicators for successful transition described in the study (including satisfaction and continuity of care)
Sattoe et al. [23]	Survey (cross-sectional)	7 participation domains; includes 'sexuality' as a separate domain Phases dichotomized; a score of 1 indicated full autonomy in participation No mention of health care component	433 young adults with various chronic conditions	Mean: 20.8 (SD = 1.9) Range: 18–25	Male: 161 (37%)	

ASD, autism spectrum disorder; CP, cerebral palsy; ESRD, end-stage renal disease; SB, spina bifida; tULRD, transversal upper limb reduction deficiency; RTP, Rotterdam Transition Profile; SD, standard deviation.

and their age-mates in all domains except that of transportation and leisure [19]. Among the eight studies, the RTP was used with study samples consisting of both male and female youth ranging from ages 14 to 31 at baseline, and with a variety of health conditions [12, 17–23]. Four studies included participants with CP [12, 17, 20, 21], two studies recruited patients with non-CP conditions (end-stage renal disease and transversal upper limb reduction deficiency) [18, 22], and the remaining two papers, which described the same study sample, enrolled participants with unspecified chronic conditions [19, 23]. Three studies excluded individuals with significant learning disabilities [12, 17, 21], four studies did not mention any learning disabilities [18, 19, 22, 23], and one study did not exclude severe learning disabilities or any intellectual levels to create a more representative sample of the adolescent population with CP [20].

Use of the RTP

The questionnaire form of the RTP was used for seven studies, with six studies using questionnaires self-reported by the patient and one study using questionnaires filled out by the researcher [12, 17–21, 23]. One study adapted the domains of the RTP into a topic list for semi-structured interviews [22]. Five papers reported having used the RTP version that contains a seventh sexuality domain separate from the intimate relationships domain [17–20, 23], and only four studies mentioned the use of the health care domains of the RTP [12, 17, 20, 21]. All three studies by Sattoe et al. [18, 19, 23] dichotomized the participation domains in order for a score of 1 to indicate full autonomy in social participation. While construct validity of the RTP has been demonstrated in young adults with CP in the original study [12], none of the subsequent papers reported reliability or validity of the RTP in adolescents and young adults with CP or other health conditions. Aside from the original validation paper, three other papers investigated associations between the RTP and other measures, including the gross motor function system (GMFCS), pediatric quality of life inventory (PedsQL), physical disability sexual and body esteem scale (PDSBES), and general self-efficacy scale (GSES) [17, 19, 20]. One study explored the association between the RTP and indicators for successful transition [23], and another used the RTP to compare social and health service participation between participants of different diagnoses [21]. In addition, the authors of six of the eight studies are all affiliated research institutions and centers in the Netherlands [12, 17–19, 22, 23], where the RTP was first developed, while the authors of

the other two papers are based in Norway and the United Kingdom [20, 21].

Materials that cited the RTP or its domains but did not use it as a measure

An additional eighteen materials consisting of published and grey literature cited the RTP or its domains in their work, but did not use the RTP as a measure. The majority of these materials mentioned the RTP as an example of a tool to assess transition readiness, with some stating its potential usefulness in clinical and research settings [10, 24–34]. Furthermore, one peer-reviewed book chapter and two theses described the RTP in detail, outlining its domains, phases, and uses [10, 35, 36]. Two conference presentation slides briefly outlined study results that used the RTP [37, 38], and one research paper stated that the questionnaire used in their study was developed via analysis of the RTP and other validated measures [39]. The Transition Research Group South West Netherlands that developed the RTP also published a paper exploring sexuality with the same CP participant group as the original RTP study, and referred in the paper to the social participation domains used in the RTP as key areas in transition [40].

Materials that cited the original RTP paper for RTP-unrelated information

The search yielded twenty-eight materials that cited the original paper on the development and validation of the RTP by Donkervoort et al. [12] for information not directly related to the RTP. For example, some studies cited information about the CP population [41–43], about the transition of young adults with disabilities [44, 45], or about specifics regarding the data collection method used by the validation study [46, 47]. These studies will not be explored further in this paper.

Discussion

This review obtained an overview of the use and utility of the RTP. The RTP appears to be a useful tool to classify social and health care participation of adolescents and young adults before, during, or after transition. It has been used by both researchers and clinicians, and with adolescents and young adults of different ages, genders, and health conditions. In research, the social participation

domains of the tool appear to be used more often without the health care domains, which could be attributed to research questions focused on social independence or on a particular participation domain, rather than on autonomy in both lifestyle and health care. For instance, Hilberink et al. [19] used the RTP with the health care domains, but focused its analysis on the social participation domains, especially the sexuality domain, as it was the most relevant to their research question regarding sexual health during pediatric rehabilitation. Many studies used the seven-domain version of the RTP that lists sexuality as a separate domain from the intimate relationships domain, which may have better suited the population they were assessing.

Moreover, while the RTP's ability to show change over time was demonstrated by Donkervoort et al. [12], the tool has mostly been used in a descriptive manner, with more researchers utilizing the RTP to assess the study sample at baseline or cross-sectionally, rather than longitudinally. Clinically, both paper questionnaire and interview formats of the tool have been used by clinicians as a useful springboard to allow for conversations about participation domains and independence with adolescents with developmental disabilities at McMaster Children's Hospital in Hamilton, Canada. To our knowledge, this tool has yet to be implemented in adult health care settings (personal communication, JWG).

Evidence on the psychometric properties of the RTP is lacking, as it has only been validated in the young adults with CP population. This lack of evidence is especially concerning as the tool has been used in research studies with varied non-CP populations, even though the RTP was originally developed and validated for people with CP. Furthermore, many studies that utilize the RTP as a measure excluded individuals with severe learning disabilities, as did the original validation study. The results of these studies are, therefore, not representative of the general population of adolescents and young adults. Additionally, since the tool was intended for use with young adults of normal intelligence, it may thus be less suitable for those individuals who do have learning disabilities, which limits the clinical utility of the RTP.

While the results show that the tool has been continually used since its development, it has not gained significant momentum over nearly 10 years as one would have expected with the recent emergence of a focus on transition and transitional planning by researchers, health care providers, and policy-makers [48–50]. A lack of developmentally suitable tools for determining transition readiness was previously deemed to hinder transition [50], and such tools and checklists, especially when validated,

should have applications in both research and clinical settings. Most researchers that employed the RTP as a measure are based in the Netherlands, where the tool was first developed, and it has not gained substantial notice outside of Europe, even though an English version of the RTP is available online through the Erasmus University Medical Center's website [51]. This slow uptake of the RTP could be partly due to its limitation in the measurement of the level of participation, as it was originally designed to classify social participation to three limited phases [12].

We would like to note two studies published after our search was conducted that used the RTP as a measure [52, 53]. Björquist et al. [52] from Sweden utilized structured interviews based on the RTP with sixteen youth immigrants with various different disabilities, of ages 16–24, and qualitatively analyzed their findings. Bal et al. [53] developed a survey used with 512 adolescents diagnosed with a range of chronic conditions, of 18–25 years of age, to compare social participation in recipients and non-recipients of disability benefits. While these studies do not considerably alter the results of our review, they demonstrate the recent use of the RTP in research.

Future work should further investigate the psychometric properties of the RTP, especially when used with populations of different diagnoses. More data supporting the validity and reliability of the RTP could promote the use of the tool in both research and clinical settings during the transition process. In addition, the utility of the tool in longitudinal studies should be further examined to determine whether it can successfully capture change.

Conclusion

The literature outlined in this review demonstrated that the RTP seems to be a useful tool to describe the transition process of adolescents and young adults cross-sectionally or at baseline, in both research and clinical settings. While it has been used with individuals of varying ages, genders, and health conditions, more evidence is needed to demonstrate its psychometric properties when used with non-CP patients.

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References

1. Reiss J, Gibson R. Health care transition: destinations unknown. *Pediatrics* 2002;110:1307–14.
2. Scal P, Evans T, Blozis S, Okinow N, Blum R. Trends in transition from pediatric to adult health care services for young adults with chronic conditions. *J Adolesc Heal* 1999;24:259–64.
3. Geenen SJ, Powers LE, Sells W. Understanding the role of health care providers during the transition of adolescents with disabilities and special health care needs. *J Adolesc Heal* 2003;32:225–33.
4. Blomquist KB, Brown G, Peersen A, Presler EP. Transitioning to independence: challenges for young people with disabilities and their caregivers. *Orthop Nurs* 1998;17:27–35.
5. Kirk S. Transitions in the lives of young people with complex healthcare needs. *Child Care Health Dev* 2008;34:567–75.
6. Young NL, Barden WS, Mills WA, Burke TA, Law M, Boydell K. Transition to adult-oriented health care: perspectives of youth and adults with complex physical disabilities. *Phys Occup Ther Pediatr* 2009;29:345–61.
7. Viner R. Transition from paediatric to adult care. Bridging the gaps or passing the buck? *Arch Dis Child* 1999;81:271–5.
8. Shanske S, Arnold J, Carvalho M, Rein J. Social workers as transition brokers: facilitating the transition from pediatric to adult medical care. *Soc Work Health Care* 2012;51:279–95.
9. Strax TE. Psychological problems of disabled adolescents and young adults. *Pediatr Ann* 1988;17:756–61.
10. Gorter JW, Roebroek M. Transition to adulthood: enhancing health and quality of life for emerging adults with neurological and developmental conditions. In: Ronen GM, Rosenbaum PL, editors. *Life quality outcomes in children and young people with neurological and developmental conditions*, 1st ed. London: Mac Keith Press, 2013:302–13. Available at: https://www.macpeds.com/documents/TransitiontoAdulthood_July2016.pdf.
11. Hallum A. Disability and the transition to adulthood: issues for the disabled child, the family, and the pediatrician. *Curr Probl Pediatr* 1995;25:12–50.
12. Donkervoort M, Wiegerink D, Van Meeteren J, Stam H, Roebroek M. Transition to adulthood: validation of the Rotterdam Transition Profile for young adults with cerebral palsy and normal intelligence. *Dev Med Child Neurol* 2009;51:53–62.
13. Chamberlain MA, Kent RM. The needs of young people with disabilities in transition from paediatric to adult services. *Eura Medicophys* 2005;41:111–23.
14. Stevens SE, Steele CA, Jutai JW, Kalnins IV, Bortolussi JA, Biggar WD. Adolescents with physical disabilities: some psychosocial aspects of health. *J Adolesc Heal* 1996;19:157–64.
15. Magill-Evans J, Wiart L, Darrah J, Kratochvil M. Beginning the transition to adulthood. *Phys Occup Ther Pediatr* 2005;25:19–36.
16. Colver AF, Merrick H, Deverill M, Le Couteur A, Parr J, Pearce MS, et al. Study protocol: longitudinal study of the transition of young people with complex health needs from child to adult health services. *BMC Public Health* 2013;13:675.
17. Hilberink SR, Kruijver E, Wiegerink DJ, Vliet Vlieland TP. A pilot implementation of an intervention to promote sexual health in adolescents and young adults in rehabilitation. *Sex Disabil* 2013;31:373–92.
18. Sattoe JN, Jedeloo S, van Staa A. Effective peer-to-peer support for young people with end-stage renal disease: a mixed methods evaluation of Camp COOL. *BMC Nephrol* 2013;14:279.
19. Sattoe JN, Hilberink SR, van Staa A, Bal R. Lagging behind or not? Four distinctive social participation patterns among young adults with chronic conditions. *J Adolesc Heal* 2014;54:397–403.
20. Ingebrigtsen TS. Effects of gross motor functioning and transition phase on health related quality of life in Norwegian adolescents with cerebral palsy. NTNU; 2015. Available at: <https://brage.bibsys.no/xmlui/handle/11250/2400015>.
21. Merrick H, McConachie H, Le Couteur A, Mann K, Parr JR, Pearce MS, et al. Characteristics of young people with long term conditions close to transfer to adult health services. *BMC Health Serv Res* 2015;15:435.
22. Lankhorst IM, Baars EC, Wijk I van, Janssen WG, Poelma MJ, van der Sluis CK. Living with transversal upper limb reduction deficiency: limitations experienced by young adults during their transition to adulthood. *Disabil Rehabil* 2017;39:1623–30.
23. Sattoe JN, Hilberink SR, van Staa A. How to define successful transition? An exploration of consensus indicators and outcomes in young adults with chronic conditions. *Child Care Health Dev* 2017;43:768–73.
24. Peeters MA, Hilberink SR, van Staa A. The road to independence: lived experiences of youth with chronic conditions and their parents compared. *J Pediatr Rehabil Med* 2014;7:33–42.
25. Tuffrey C. Adolescents with physical disability: seeing the individual in context. *Arch Dis Child* 2013;98:373–7.
26. Gleeson H, Turner G. Transition to adult services. *Arch Dis Child* 2012;97:86–92.
27. McDonagh JE, Kelly DA. The challenges and opportunities for transitional care research. *Pediatr Transplant* 2010;14:688–700.
28. Ketelaar M, Wassenberg-Severijnen J. Developments in measuring functional activities: where do we go with the PEDI-CAT? *Phys Occup Ther Pediatr* 2010;30:185–9.
29. Geerlings RP, Aldenkamp AP, Gottmer-Welschen LM, de With PH, Zinger S, van Staa AL, et al. Evaluation of a multidisciplinary epilepsy transition clinic for adolescents. *Eur J Paediatr Neurol* 2016;20:385–92.
30. NICE guideline: Transition from children's to adult services for young people using health or social care services. London, 2016. Available at: <https://www.nice.org.uk/guidance/ng43/documents/transition-from-childrens-to-adult-services-final-scope3>.
31. Morgan P. To gain new knowledge regarding optimising physical function in adults ageing with cerebral palsy. Canberra, 2017. Available at: https://www.churchilltrust.com.au/media/fellows/Morgan_P_2016_Optimising_physical_function_in_adults_ageing_with_cerebral_palsy.pdf.

32. Transition: key themes & principles. Yorkshire & the Humber; 2014. Available at: <http://www.londonscn.nhs.uk/wp-content/uploads/2015/07/cyp-yath-052015.pdf>.
33. McDonagh JE. Growing up ready, moving on well: the ongoing challenge of transitional care. In p. 1–29. Available from: http://www.ayph.org.uk/publications/213_Growingupreadytomoveonwell-DrJanetMcDonagh.ppt
34. Roebroek M. Transition to adulthood: promoting autonomy of emerging adults with childhood-onset disabilities. *Dev Med Child Neurol* 2013;55:9.
35. Björquist E. Living in transition to adulthood: adolescents with cerebral palsy and their parents' experiences of health, well-being and needs. Lund University, 2013. Available at: http://www.fyrbodal.se/download/18.784dc92d14d4fb74d6a86ab9/1431956734753/Bjorquist_lic_thesis_131125.pdf.
36. Björquist E. Mind the gap: transition to adulthood - youths' with disabilities and their caregivers' perspectives. Lund University, 2016. Available at: <http://portal.research.lu.se/portal/files/8032722/8871324.pdf>.
37. Gorter JW, Morrison A, Hlyva O. Transition to adulthood with cyber guide evaluation study: emergent transition profiles among youth with chronic health conditions. In: Ontario Association of Children's Rehabilitation Services (OACRS) Annual Conference 2012:1–60. Available at: https://canchild.ca/system/tenon/assets/attachments/000/000/683/original/trace_transition_workshop_2012.pdf.
38. Hidecker MJ. Functional profiles & transition areas for adolescents & adults with cerebral palsy. In: *Cerebral palsy in 3D: disability, disparities, developments*. Ann Arbor, 2015:1–22. Available at: <http://www.epi.msu.edu/cpon/presentations/cpin3d/Hidecker-FunctionalProfiles.pdf>.
39. Piazza B, Hennrikus W, Schell R, Armstrong D, Fortuna K. The factors most important for quality of life in children and adolescents with cerebral palsy. *J Pediatr Neurol Med* 2016;1:102.
40. Wiegerink D, Roebroek M, Bender J, Stam H, Cohen-Kettenis P, Netherlands TR. Sexuality of young adults with cerebral palsy: experienced limitations and needs. *Sex Disabil* 2011;29: 119–28.
41. Michelsen SI, Flachs EM, Damsgaard MT, Parkes J, Parkinson K, Rapp M, et al. European study of frequency of participation of adolescents with and without cerebral palsy. *Eur J Paediatr Neurol* 2014;18:282–94.
42. Smits D-W, Ketelaar M, Gorter JW, van Schie P, Dallmeijer A, Jongmans M, et al. Development of daily activities in school-age children with cerebral palsy. *Res Dev Disabil* 2011;32:222–34.
43. Wiegerink DJ, Stam HJ, Ketelaar M, Cohen-Kettenis PT, Roebroek ME. Personal and environmental factors contributing to participation in romantic relationships and sexual activity of young adults with cerebral palsy. *Disabil Rehabil* 2012;34:1481–7.
44. Gorter JW, Stewart D, Smith MW, King G, Wright M, Nguyen T, et al. Pathways toward positive psychosocial outcomes and mental health for youth with disabilities: a knowledge synthesis of developmental trajectories. *Can J Community Ment Heal* 2014;33:45–61.
45. Tuffrey C, Bateman BJ, Colver AC. The Questionnaire of Young People's Participation (QYPP): a new measure of participation frequency for disabled young people. *Child Care Health Dev* 2013;39:500–11.
46. Benner JL, Hilberink SR, Veenis T, Stam HJ, Van Der Slot WM, Roebroek ME. Long-term deterioration of perceived health and functioning in adults with cerebral palsy. *Arch Phys Med Rehabil* 2017;98:2196–205.
47. Benner JL, Hilberink SR, Veenis T, van der Slot WM, Roebroek ME. Course of employment in adults with cerebral palsy over a 14-year period. *Dev Med Child Neurol* 2017;59: 762–8.
48. Lotstein DS, McPherson M, Strickland B, Newacheck PW. Transition planning for youth with special health care needs: results from the national survey of children with special health care needs. *Pediatrics* 2005;115:1562–8.
49. Gorter JW, Stewart D, Woodbury-Smith M. Youth in transition: care, health and development. *Child Care Health Dev* 2011;37:757–63.
50. American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, Transitions Clinical Report Authoring Group. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics* 2011;128:182–200.
51. Wiegerink D, Donkervoort M, Roebroek M. The Rotterdam Transition Profile [Internet]. Rotterdam, 2007. Available at: <https://www.erasmusmc.nl/Reva/Research/transition/RotterdamTransitionProfilev0.2>.
52. Björquist E, Nordmark E, Almasri NA, Hallström I. Immigrant youths with disabilities and caregivers from the Middle-East – challenges and needs during transition to adulthood. *Res Heal Sci* 2017;2:363.
53. Bal MI, Sattoe JN, Miedema HS, van Staa A. Social participation and psychosocial outcomes of young adults with chronic physical conditions: comparing recipients and non-recipients of disability benefits. *Ann Phys Rehabil Med* 2018;61: 85–91.