



STUDY PROTOCOL

# Transition from child-centred to adult-oriented healthcare systems for young people with neurodisability: a scoping review protocol [version 1; peer review: 3 approved]

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## Abstract

**Background:** The transition from child-centred to adult-oriented healthcare is a challenging time for young people with neurodisability. As the prevalence of neurodisability increases, greater numbers of young people will eventually transfer to the adult healthcare system. While there is a growing recognition of the importance of providing quality, transitional care, little is known about how to manage and optimise this process for young people with neurodisability. The objective of this scoping review is to examine and map existing literature related to the transition from child-centred to adult-oriented healthcare systems for young people with neurodisability.

**Methods:** Systematic literature searches of OVID MEDLINE, EMBASE, PsycINFO, CINAHL, Cochrane Library and Web of Science will be conducted from inception to present. A structured iterative search of grey literature will be conducted. This review will consider all study designs examining the transition from child to adult health services in neurodisability. Two reviewers will independently screen each retrieved title and abstract and assess full-text articles against the inclusion criteria to determine eligibility. Data will be extracted and synthesised quantitatively and qualitatively. The process and reporting will follow PRISMA-ScR guidelines.

**Conclusion:** This review will provide a broad and systematically mapped synthesis of the extent and nature of the available published and unpublished literature on transition from child-centred to adult-oriented healthcare systems in neurodisability. The results will be used to determine gaps in the current evidence base in order to prioritise areas for future research.

## Open Peer Review

Reviewer Status

Invited Reviewers

	1	2	3
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Any reports and responses or comments on the article can be found at the end of the article.

**Keywords**

neurodisability, neurodevelopmental disorders, transition to adult care, transitional care, young adult, adolescent, scoping review

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## Introduction

Neurodisability describes congenital or acquired long-term conditions that are attributed to impairment of the brain and/or neuromuscular system and create functional limitations<sup>1</sup>. Neurodisability encompasses conditions characterised by physical, intellectual, behavioural or sensory impairments, such as cerebral palsy, autism spectrum disorders and epilepsy<sup>2</sup>. The prevalence of neurodisability is increasing<sup>3</sup>. Individually, many conditions in this heterogeneous group are rare but when grouped together they are common<sup>4</sup>. Children and young people (CYP) with neurodisability represent between 6 and 9% of the general population<sup>5-7</sup>. Advances in medical management and treatment mean many CYP with neurodisability are surviving to need care as adults<sup>8-10</sup>.

The transition from adolescence to adulthood is associated with profound physiological, psychological, and social changes<sup>11</sup> as young people orientate towards a greater degree of independence in many concurrent areas including relationships, housing, education and employment<sup>12</sup>. The complexity of this process is amplified for CYP with long-term conditions who are simultaneously negotiating the developmental process of adolescence and independence in managing a long-term condition<sup>13</sup>. Adaptation from a supported environment to one of individual responsibility and independence in self-advocacy and management during this developmental phase is particularly challenging for individuals with neurodisability who may have communication, physical or learning difficulties, higher rates of comorbid health problems<sup>1</sup>, and who utilise healthcare services more intensively than their peers<sup>14,15</sup>.

The term transition has been adopted to describe the complex and continuous process of preparing CYP with long-term conditions to move from child-centred to adult-oriented healthcare systems<sup>16</sup>. Transition is therefore distinct from transfer, the latter being considered as a one-time event when the young person moves from a child-centred to adult-oriented healthcare setting<sup>17</sup>. The transition process aims to maximise potential and lifelong functioning through the provision of cohesive and continuous, developmentally appropriate healthcare as the individual moves to adult health services<sup>18</sup>. Ideally, this process is coordinated, comprehensive, and patient-centred spanning adolescence to adulthood<sup>18</sup>, preferably beginning when the individual is 13–14 years of age and continuing until they are capable of taking full responsibility for their health<sup>19</sup>. However, the transition process is frequently turbulent and experienced negatively by CYP, their families and caregivers<sup>20</sup>. Obstacles to successfully implementing transition include funding limitations, lack of continuity and coordination between child and adult services<sup>21-23</sup> and limited training opportunities and specialist expertise in the adult system<sup>24-27</sup>. In addition, there are significant changes to healthcare provider relationship and reduced support levels in the adult environment<sup>28</sup>.

Suboptimal transition to adult health care is associated with diminished treatment adherence and interruption or loss to follow-up<sup>29</sup>. This discontinuity leaves CYP vulnerable to adverse health consequences including functional

decrements, medical complications and a heightened risk of hospital admissions<sup>30-32</sup> as well as poor psychological, social and vocational outcomes<sup>12,33-36</sup>. Preventing such declines for CYP with neurodisability is a healthcare priority<sup>19</sup>. This is reflected in the increasing volume of research examining transition and transfer of care in neurodisability in recent years.

To date, literature has explored effective and efficient features of transition practices and programmes<sup>37-40</sup>, explored the perspectives of healthcare professionals<sup>25,26</sup> and experiences of young people and their families<sup>34,41-44</sup> and the impact of transitional care on measurable outcomes<sup>45-47</sup>. A number of scoping reviews have explored transition among CYP with physical<sup>48</sup>, mental health<sup>49,50</sup> and endocrine, neurological and gastrointestinal conditions<sup>51,52</sup>. Evidence from these reviews may not be generalizable to neurodisability due to the range and complexity of these conditions and the greater need for service coordination<sup>53</sup>. A scoping review protocol by Bogassian and colleagues is the only one available looking specifically at transition and neurodisability<sup>54</sup>. However, their review focus considers the ethical issues encountered in transition programmes only. Young people with neurodisability constitute a unique and growing population to whom a well-managed and executed transition process can be valuable. Therefore, a comprehensive synthesis of the literature on transition for CYP with neurodisability is needed to consider what is known in order to guide future research and improve transition care.

A scoping review will be undertaken to explore existing literature relating to transition for CYP with neurodisability. This methodology is appropriate as it will provide a comprehensive map of key concepts underpinning the research area and a substantial overview of the types and sources of evidence available in the current body of literature<sup>55</sup>. It will clarify the aspects of transition which have been the focus of research initiatives to date and identify any knowledge gaps or research deficits that exist within the field that require further research<sup>55,56</sup>.

## Methods

### Design

The methodology for this review draws on the five-stage framework outlined by Arksey and O'Malley<sup>55</sup> and more recent refinements to the methodology proposed by Levac *et al.*<sup>56</sup> and the Joanna Briggs Institute (JBI)<sup>57</sup>. The optional sixth stage, 'consultation with relevant stakeholders' will not be included as part of this review. This protocol follows the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA- ScR) guidelines<sup>58</sup> to ensure rigour in reporting.

### Stage 1: Identifying the research questions

The primary aim of this review is to determine and describe the extent and nature of available evidence addressing transition for CYP with neurodisability and to identify gaps in the existing literature.

Several secondary questions will guide the subsequent stages of the scoping review.

1. What is the current volume and yearly distribution of evidence on transition in CYP with neurodisability?
2. What types of studies on transition in CYP with neurodisability have been conducted (e.g. quantitative, qualitative or mixed-method methodologies)?
3. In which settings and geographical contexts have previous transition studies in neurodisability been conducted?
4. Which conditions have been included in previous studies?
5. How has the concept of 'transition' been defined, operationalised and measured in the literature in relation to people with neurodisability?
6. What involvement did CYP and their family/caregivers have in the design, conduct and dissemination of the research?
7. Which theories, models or frameworks have been used to inform transition in neurodisability?

### Inclusion criteria

The inclusion criteria for this scoping review will be guided by the population, concepts and context (PCC) approach<sup>56</sup>. Inclusion and exclusion criteria are summarised in [Table 1](#).

**Participants.** A multitude of definitions for neurodisability exist in the literature. Historically the group of conditions encompassed by the term neurodisability were interchangeably referred to as neurodevelopmental disorders<sup>59</sup> or neurodevelopmental disabilities<sup>60</sup>. For uniformity, the term used throughout will be neurodisability. In the context of this review, we will define neurodisability as "A group of congenital or acquired long-term conditions that are attributed to impairment of the brain and/or neuromuscular system and create functional limitations. A specific diagnosis may or may not be identified. Conditions may vary over time, occur alone or in combination, and include a vast range of severity and complexity"<sup>1</sup>. For the purpose of this review we will include people who experience disturbances of movement, cognition, communication or emotion and behaviour. Studies including male and female CYP with neurodisability will be included. Studies that focus on families, caregivers, health care providers, programme managers and policymakers involved in the transition process will be included.

**Concept.** The concept examined by this scoping review is the transition from child-centred to adult-orientated healthcare systems. In the context of this review we will define transition as "a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with long-term physical and medical conditions as they move from child-centred to adult oriented healthcare systems"<sup>16</sup>.

**Context.** This scoping review will consider studies on transition that have been conducted in any setting such as hospitals, healthcare settings, acute care, primary care, special care, home-care or the community. The context will not be limited to specific geographic location.

**Types of evidence sources.** The review will consider studies of any design that address transition including qualitative, quantitative and mixed-methods methodology. Quantitative studies will include both experimental (e.g., randomised trials, non-randomised trials) and observational (e.g., cohort, cross-sectional) study designs. Case series and individual case reports will also be included. Qualitative studies will include designs such as grounded theory, ethnography, phenomenology, action research and qualitative descriptive. Text and opinion papers will be considered for inclusion if they are published in peer-reviewed journals. In addition, all types of reviews (e.g., systematic reviews, narrative reviews) will be included. Grey literature will also be considered for inclusion in the review.

### Stage 2: Identifying relevant studies

A comprehensive search strategy was developed in consultation with an information specialist. To develop the search strategy, an initial limited search was conducted in OVID MEDLINE and CINAHL to identify articles relevant to the topic area. Key words and index terms were identified from the title and abstract of relevant articles and used to inform the search strategy. Search terms included key words and index terms relating to neurodisability, transition and young people. The search strategy for OVID MEDLINE can be found in the online supplementary material (see *Extended data*<sup>61</sup>). It will be modified as necessary for the other databases. We will search the following electronic databases from inception to the present date: OVID MEDLINE, EMBASE, PsycINFO, CINAHL, Cochrane Library and Web of Science. We will also perform

**Table 1. Inclusion and exclusion criteria of study selection.**

Inclusion	Exclusion
Studies related to transition from child-centred to adult-oriented healthcare systems	Subject of the study is not related to transition from child-centred to adult-oriented healthcare systems
Study sample includes people with neurodisability, families and caregivers of people with neurodisability or health care providers, programme managers and policymakers who work with people with neurodisability	Study sample does not include people with neurodisability, families and caregivers of people with neurodisability or health care providers, programme managers and policymakers who work with people with neurodisability
Studies published in English	Non-English language studies

targeted searches for grey literature through OpenGrey, BASE (Bielefeld Academic Search Engine) and Google. Finally, the literature search will be supplemented by hand searching reference lists of included reports. Only reports published in English will be included. Literature searches will be completed by an information specialist.

### Stage 3: Study selection

All identified citations will be collated and uploaded into End-Note (Clarivate Analytics, PA, USA), and duplicates removed. Two reviewers will independently screen the titles and abstracts of the literature search results considering the eligibility criteria for the review using Rayyan QCRI<sup>62</sup>. Full texts of potentially eligible studies will be obtained and reviewed by two reviewers independently. Prior to commencing the screening process, two reviewers will conduct a calibration exercise to ensure reliability in correctly screening for inclusion. It will entail independently screening a random sample of the included citations by each reviewer. If low agreement is observed between the reviewers, eligibility criteria will be modified. Discrepancies will be resolved by discussion between reviewers. A third reviewer will be consulted if consensus is not achieved between reviewers.

### Stage 4: Charting the data

Data charting will be conducted using a standardised form, developed from the JBI data extraction tool<sup>57</sup>. Two reviewers will independently pilot the form on a random sample of included reports. If poor agreement is found, the data extraction form will be revised iteratively and the training exercise will be repeated<sup>55</sup>. The data charted will include specific details about the population, concept, context, study methods and key findings of significance to the scoping review objective and questions. Authors of papers will be contacted to request missing or additional data, where required. A quality appraisal will not be undertaken in keeping with guidance on scoping review conduct<sup>63</sup>.

### Stage 5: Collating, summarising and reporting the results

Results of the literature search and study screening process will be presented in a PRISMA-ScR flow diagram<sup>58</sup>. Charted data will be synthesised quantitatively and qualitatively. For example, summary statistics will be used to

describe the current volume, yearly distribution, countries of origin, sample characteristics and methodological design. Key concepts will be summarised using descriptive content analysis. Results will be presented in tabular, graphic or diagrammatical formats according to key findings and knowledge gaps.

### Study status

At the time of publication of this protocol, database searches have been completed.

### Discussion

Given the challenges experienced by CYP with neurodisability during the transition to adult health care, there is an urgent need to better understand this process. This scoping review will broadly and systematically explore what is known about transition in neurodisability. Findings will be used to identify knowledge gaps to direct future research and provide a foundation for developing research priorities. The findings of the review will be published in an open-source journal, presented at national and international conferences, and shared with clinicians, young people and families through organisations for people with disability.

### Data availability

#### Underlying data

No underlying data are associated with this article.

#### Extended data

Open Science Framework: Transition from child-centred to adult-oriented healthcare systems for young people with neurodisability: a scoping review protocol. <https://doi.org/10.17605/OSF.IO/DX8ZF><sup>61</sup>.

This project contains the following extended data:

- OVID MEDLINE search strategy.pdf
- Draft data charting\_data extraction template.pdf
- PRISMA-P checklist.pdf

Extended data are available under the terms of the [Creative Commons Zero “No rights reserved” data waiver](#) (CC0 1.0 Public domain dedication).

## References

1. Morris C, Janssens A, Tomlinson R, *et al.*: **Towards a definition of neurodisability: a Delphi survey.** *Dev Med Child Neurol.* 2013; **55**(12): 1103-8. [PubMed Abstract](#) | [Publisher Full Text](#)
2. Brown M, Higgins A, MacArthur J: **Transition from child to adult health services: A qualitative study of the views and experiences of families of young adults with intellectual disabilities.** *J Clin Nurs.* 2020; **29**(1-2): 195-207. [PubMed Abstract](#) | [Publisher Full Text](#)
3. Houtrow AJ, Larson K, Olson LM, *et al.*: **Changing trends of childhood disability, 2001-2011.** *Pediatrics.* 2014; **134**(3): 530-8. [PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
4. Morris C, Janssens A, Shilling V, *et al.*: **Meaningful health outcomes for paediatric neurodisability: Stakeholder prioritisation and appropriateness of patient reported outcome measures.** *Health Qual Life Outcomes.* 2015; **13**: 87. [PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)

5. Blackburn CM, Spencer NJ, Read JM: **Prevalence of childhood disability and the characteristics and circumstances of disabled children in the UK: secondary analysis of the Family Resources Survey.** *BMC Pediatr.* 2010; **10**: 21.  
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
6. Arim RG, Miller AR, Guèvremont A, et al.: **Children with neurodevelopmental disorders and disabilities: a population-based study of healthcare service utilization using administrative data.** *Dev Med Child Neurol.* 2017; **59**(12): 1284–90.  
[PubMed Abstract](#) | [Publisher Full Text](#)
7. Lach LM, Kohen DE, Garner RE, et al.: **The health and psychosocial functioning of caregivers of children with neurodevelopmental disorders.** *Disabil Rehabil.* 2009; **31**(8): 607–18.  
[PubMed Abstract](#) | [Publisher Full Text](#)
8. Tuffrey C, Pearce A: **Transition from paediatric to adult medical services for young people with chronic neurological problems.** *J Neurol Neurosurg Psychiatry.* 2003; **74**(8): 1011–3.  
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
9. Brooks JC, Strauss DJ, Shavelle RM, et al.: **Recent trends in cerebral palsy survival. Part II: individual survival prognosis.** *Dev Med Child Neurol.* 2014; **56**(11): 1065–71.  
[PubMed Abstract](#) | [Publisher Full Text](#)
10. Shin M, Kucik JE, Siffel C, et al.: **Improved survival among children with spina bifida in the United States.** *J Pediatr.* 2012; **161**(6): 1132–7.  
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
11. Wood D, Crapnell T, Lau L, et al.: **Emerging Adulthood as a Critical Stage in the Life Course.** In: Halfon N, Forrest CB, Lerner RM, Faustman EM, editors. *Handbook of Life Course Health Development.* Cham: Springer International Publishing; 2018; 123–43.  
[PubMed Abstract](#) | [Publisher Full Text](#)
12. Donkervoort M, Wiegink DJHG, Van Meeteren J, et al.: **Transition to adulthood: validation of the Rotterdam Transition Profile for young adults with cerebral palsy and normal intelligence.** *Dev Med Child Neurol.* 2009; **51**(1): 53–62.  
[PubMed Abstract](#) | [Publisher Full Text](#)
13. Willis ER, McDonagh JE: **Transition from children's to adults' services for young people using health or social care services (NICE Guideline NG43).** *Arch Dis Child Educ Pract Ed.* 2018; **103**(5): 253–6.  
[PubMed Abstract](#) | [Publisher Full Text](#)
14. Yuan JX, McGowan M, Hadjikhouri I, et al.: **Do children with neurological disabilities use more inpatient resources: an observational study.** *Emerg Themes Epidemiol.* 2017; **14**: 5.  
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
15. Berry JG, Poduri A, Bonkowski JL, et al.: **Trends in resource utilization by children with neurological impairment in the United States inpatient health care system: a repeat cross-sectional study.** *PLoS Med.* 2012; **9**(1): e1001158.  
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
16. Blum RW, Garell D, Hodgman CH, et al.: **Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine.** *J Adolesc Health.* 1993; **14**(7): 570–6.  
[PubMed Abstract](#) | [Publisher Full Text](#)
17. Colver A, McConachie H, Le Couteur A, et al.: **A longitudinal, observational study of the features of transitional healthcare associated with better outcomes for young people with long-term conditions.** *BMC Med.* 2018; **16**(1): 111.  
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
18. American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians-American Society of Internal Medicine: **A consensus statement on health care transitions for young adults with special health care needs.** *Pediatrics.* 2002; **110**(6 Pt 2): 1304–6.  
[PubMed Abstract](#)
19. NICE NiHACE: **Transition from children's to adults' services for young people using health or social care services.** 2016.  
[Reference Source](#)
20. Sonneveld HM, Strating MM, van Staa AL, et al.: **Gaps in transitional care: what are the perceptions of adolescents, parents and providers?** *Child Care Health Dev.* 2013; **39**(1): 69–80.  
[PubMed Abstract](#) | [Publisher Full Text](#)
21. Burke L, Kirkham J, Arnott J, et al.: **The transition of adolescents with juvenile idiopathic arthritis or epilepsy from paediatric health-care services to adult health-care services: A scoping review of the literature and a synthesis of the evidence.** *J Child Health Care.* 2018; **22**(3): 332–58.  
[PubMed Abstract](#) | [Publisher Full Text](#)
22. Lindsay S, Cruickshank H, McPherson AC, et al.: **Implementation of an inter-agency transition model for youth with spina bifida.** *Child Care Health Dev.* 2016; **42**(2): 203–12.  
[PubMed Abstract](#) | [Publisher Full Text](#)
23. Okumura MJ, Kerr EA, Cabana MD, et al.: **Physician views on barriers to primary care for young adults with childhood-onset chronic disease.** *Pediatrics.* 2010; **125**(4): e748–54.  
[PubMed Abstract](#) | [Publisher Full Text](#)
24. Young NL, Barden WS, Mills WA, et al.: **Transition to adult-oriented health care: perspectives of youth and adults with complex physical disabilities.** *Phys Occup Ther Pediatr.* 2009; **29**(4): 345–61.  
[PubMed Abstract](#) | [Publisher Full Text](#)
25. Ally S, Boyd K, Abells D, et al.: **Improving transition to adulthood for adolescents with intellectual and developmental disabilities: Proactive developmental and systems perspective.** *Can Fam Physician.* 2018; **64** (Suppl 2): S37–S43.  
[PubMed Abstract](#) | [Free Full Text](#)
26. Chung RJ, Jasien J, Maslow GR: **Resident Dyads Providing Transition Care to Adolescents and Young Adults With Chronic Illnesses and Neurodevelopmental Disabilities.** *J Grad Med Educ.* 2017; **9**(2): 222–227.  
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
27. Hart LC, Deussen RV, Gonzaga AM: **Pediatric residents' attitudes and practice patterns regarding transition to adult-oriented care.** *J Commun Healthc.* 2017; **10**(2): 149–155.  
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
28. DiFazio RL, Harris M, Vessey JA, et al.: **Opportunities lost and found: experiences of patients with cerebral palsy and their parents transitioning from pediatric to adult healthcare.** *J Pediatr Rehabil Med.* 2014; **7**(1): 17–31.  
[PubMed Abstract](#) | [Publisher Full Text](#)
29. Coyne I, Sheehan A, Heery E, et al.: **Healthcare transition for adolescents and young adults with long-term conditions: Qualitative study of patients, parents and healthcare professionals' experiences.** *J Clin Nurs.* 2019; **28** (21–22): 4062–76.  
[PubMed Abstract](#) | [Publisher Full Text](#)
30. Lotstein DS, Seid M, Klingensmith G, et al.: **Transition from pediatric to adult care for youth diagnosed with type 1 diabetes in adolescence.** *Pediatrics.* 2013; **131**(4): e1062–70.  
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
31. Nakhla M, Daneman D, To T, et al.: **Transition to adult care for youths with diabetes mellitus: findings from a Universal Health Care System.** *Pediatrics.* 2009; **124**(6): e1134–41.  
[PubMed Abstract](#) | [Publisher Full Text](#)
32. Yeung E, Kay J, Roosevelt GE, et al.: **Lapse of care as a predictor for morbidity in adults with congenital heart disease.** *Int J Cardiol.* 2008; **125**(1): 62–5.  
[PubMed Abstract](#) | [Publisher Full Text](#)
33. Camfield PR, Andrade D, Camfield CS, et al.: **How can transition to adult care be best orchestrated for adolescents with epilepsy?** *Epilepsy Behav.* 2019; **93**: 138–47.  
[PubMed Abstract](#) | [Publisher Full Text](#)
34. Both P, Ten Holt L, Mous S, et al.: **Tuberous sclerosis complex: Concerns and needs of patients and parents from the transitional period to adulthood.** *Epilepsy Behav.* 2018; **83**: 13–21.  
[PubMed Abstract](#) | [Publisher Full Text](#)
35. Young N, McCormick A, Mills W, et al.: **The transition study: a look at youth and adults with cerebral palsy, spina bifida and acquired brain injury.** *Phys Occup Ther Pediatr.* 2006; **26**(4): 25–45.  
[PubMed Abstract](#)
36. Wisk LE, Weitzman ER: **Expectancy and Achievement Gaps in Educational Attainment and Subsequent Adverse Health Effects Among Adolescents With and Without Chronic Medical Conditions.** *J Adolesc Health.* 2017; **61**(4): 461–70.  
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
37. Colver A, Rapley T, Parr JR, et al.: **Facilitating the transition of young people with long-term conditions through health services from childhood to adulthood: the Transition research programme.** *Programme Grants Appl Res.* 2019; **7**(4): 1–244.  
[Publisher Full Text](#)
38. Campbell F, Biggs K, Aldiss SK, et al.: **Transition of care for adolescents from paediatric services to adult health services.** *Cochrane Database Syst Rev.* 2016; **4**: Cd009794.  
[PubMed Abstract](#) | [Publisher Full Text](#)
39. Binks JA, Barden WS, Burke TA, et al.: **What do we really know about the transition to adult-centered health care? A focus on cerebral palsy and spina bifida.** *Arch Phys Med Rehabil.* 2007; **88**(8): 1064–73.  
[PubMed Abstract](#) | [Publisher Full Text](#)
40. Davis AM, Brown RF, Taylor JL, et al.: **Transition care for children with special health care needs.** *Pediatrics.* 2014; **134**(5): 900–8.  
[Publisher Full Text](#)
41. Patel SK, Staarmann B, Heilman A, et al.: **Growing up with spina bifida: bridging the gaps in the transition of care from childhood to adulthood.** *Neurosurg Focus.* 2019; **47**(4): E16.  
[PubMed Abstract](#) | [Publisher Full Text](#)
42. Jacobs P, MacMahon K, Quayle E: **Transition from school to adult services for young people with severe or profound intellectual disability: A systematic review utilizing framework synthesis.** *J Appl Res Intellect Disabil.* 2018; **31**(6): 962–82.  
[PubMed Abstract](#) | [Publisher Full Text](#)
43. Carroll EM: **Health Care Transition Experiences of Young Adults With Cerebral Palsy.** *J Pediatr Nurs.* 2015; **30**(5): e157–64.  
[PubMed Abstract](#) | [Publisher Full Text](#)
44. Thompson C, Bolte S, Falkmer T, et al.: **To be understood: Transitioning to adult life for people with Autism Spectrum Disorder.** *PLoS One.* 2018; **13**(3):

- e0194758.  
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
45. Coyne B, Hollowell SC, Thompson M: **Measurable Outcomes After Transfer From Pediatric to Adult Providers in Youth With Chronic Illness.** *J Adolesc Health.* 2017; **60**(1): 3–16.  
[PubMed Abstract](#) | [Publisher Full Text](#)
  46. Howard SW, Zhang Z, Buchanan P, et al.: **The Effect of a Comprehensive Care Transition Model on Cost and Utilization for Medically Complex Children With Cerebral Palsy.** *J Pediatr Health Care.* 2017; **31**(6): 634–47.  
[PubMed Abstract](#) | [Publisher Full Text](#)
  47. Janssens A, Rogers M, Gumm R, et al.: **Measurement properties of multidimensional patient-reported outcome measures in neurodisability: a systematic review of evaluation studies.** *Dev Med Child Neurol.* 2016; **58**(5): 437–51.  
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
  48. Freeman M, Stewart D, Cunningham CE, et al.: **Information needs of young people with cerebral palsy and their families during the transition to adulthood: a scoping review.** 2018; (1): 20180003.  
[Publisher Full Text](#)
  49. Reale L, Bonati M: **Mental disorders and transition to adult mental health services: A scoping review.** *Eur Psychiatry.* 2015; **30**(8): 932–42.  
[PubMed Abstract](#) | [Publisher Full Text](#)
  50. Di Rezze B, Nguyen T, Mulvale G, et al.: **A scoping review of evaluated interventions addressing developmental transitions for youth with mental health disorders.** *Child: care, health and development.* 2016; **42**(2): 176–87.  
[PubMed Abstract](#) | [Publisher Full Text](#)
  51. Acuña Mora M, Saarijärvi M, Moons P, et al.: **The Scope of Research on Transfer and Transition in Young Persons With Chronic Conditions.** *J Adolesc Health.* 2019; **65**(5): 581–9.  
[PubMed Abstract](#) | [Publisher Full Text](#)
  52. Rohatinsky N, Risling T, Kumaran M, et al.: **Healthcare Transition in Pediatrics and Young Adults With Inflammatory Bowel Disease: A Scoping Review.** *Gastroenterol Nurs.* 2018; **41**(2): 145–58.  
[PubMed Abstract](#) | [Publisher Full Text](#)
  53. Solanke F, Colver A, McConachie H: **Are the health needs of young people with cerebral palsy met during transition from child to adult health care?** *Child Care Health Dev.* 2018; **44**(3): 355–63.  
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
  54. Bogossian A, Gorter JW, Racine E: **Protocol for a scoping review about ethics in transition programmes for adolescents and young adults with neurodisabilities.** *BMJ Open.* 2018; **8**(8): e020914.  
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
  55. Arksey H, O'Malley L: **Scoping studies: towards a methodological framework.** *Int J Soc Res Methodol.* 2005; **8**(1): 19–32.  
[Publisher Full Text](#)
  56. Levac D, Colquhoun H, O'Brien KK: **Scoping studies: advancing the methodology.** *Implement Sci.* 2010; **5**(1): 69.  
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
  57. Peters MDJ, Godfrey C, McInerney P, et al.: **Chapter 11: Scoping Reviews (2020 version).** 2020.  
[Reference Source](#)
  58. Tricco AC, Lillie E, Zarin W, et al.: **PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation.** *Ann Intern Med.* 2018; **169**(7): 467–73.  
[PubMed Abstract](#) | [Publisher Full Text](#)
  59. Chen CY, Liu CY, Su WC, et al.: **Factors associated with the diagnosis of neurodevelopmental disorders: a population-based longitudinal study.** *Pediatrics.* 2007; **119**(2): e435–43.  
[PubMed Abstract](#) | [Publisher Full Text](#)
  60. Accardo J, Shapiro BK: **Neurodevelopmental disabilities: beyond the diagnosis.** *Semin Pediatr Neurol.* 2005; **12**(4): 242–9.  
[PubMed Abstract](#) | [Publisher Full Text](#)
  61. Fortune J, Ryan J: **Transition from child-centred to adult-oriented healthcare systems for young people with neurodisability: a scoping review protocol.** 2020.  
<http://www.doi.org/10.17605/OSF.IO/DX8ZF>
  62. Ouzzani M, Hammady H, Fedorowicz Z, et al.: **Rayyan—a web and mobile app for systematic reviews.** *Syst Rev.* 2016; **5**(1): 210.  
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
  63. Peters MDJ, Godfrey CM, Khalil H, et al.: **Guidance for conducting systematic scoping reviews.** *Int J Evid Based Healthc.* 2015; **13**(3): 141–6.  
[PubMed Abstract](#) | [Publisher Full Text](#)

## Open Peer Review

Current Peer Review Status:   

### Version 1

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**Katherine Langdon** 

Department of Paediatric Rehabilitation, Perth Children's Hospital, Nedlands, WA, Australia

Thanks for the opportunity to comment. I wonder what issues you will find in the search to pin down the research question? There are many unique circumstances that ought to be addressed. There is variability between the neurodisabilities in the health related comorbidities and the earlier these occur, the better they are described and the more dire the outcomes in the event of poor management, the more likely that these conditions will have a transition process in place e.g. spina bifida. Where serious health related problems occur later in the trajectory of a condition e.g. cerebral palsy, the more lacklustre the transition program in my experience.

Success or otherwise is also dependent on the agency of the child which is a subject I have not seen much research about in the disability literature.

Children in state care are a unique problem in transition programs as medical transition can be accompanied by a transition in housing and guardianship.

The adult perspective of graduates of childhood conditions is also unpredictable and influences the willingness of adult engagement. Severe disability can be met with the automatic presumption of "palliation" and with it an assumption that death is "imminent" despite the child already having lived for 17 or so years, once services are sought in the adult sector and levels of care can be set on the basis of these value judgments. While it may not come into the scope of your questions, I wonder too whether CYP with congenital disabilities are not differentiated from adults with acquired disabilities who have lost skills they once had. I wonder whether this too affects the interest level in adult engagement with paediatric neurodisability graduates. There is a need to look into these clinically relevant scenarios witnessed in practice but not (yet?) in the literature.

**Is the rationale for, and objectives of, the study clearly described?**

Yes

**Is the study design appropriate for the research question?**



Yes

**Are sufficient details of the methods provided to allow replication by others?**

Yes

**Are the datasets clearly presented in a useable and accessible format?**

Not applicable

**Competing Interests:** No competing interests were disclosed.

**Reviewer Expertise:** paediatric cerebral palsy, spinal cord pathology, acquired brain injury

**I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.**

Reviewer Report 10 November 2020

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**Divya Jindal-Snape** 

Transformative Change: Education and Life Transitions (TCELT) Research Centre, School of Education and Social Work, University of Dundee, Dundee, UK

This article presents the protocol for a scoping review that will map previous literature on transitions of children and young people with neurodisability as they move from child- to adult-centred healthcare systems. This includes investigating the key concepts, and nature and type of evidence presented in this literature.

This is an important area of research. The protocol is clearly structured with explicit and transparent methodology. Most transitions researchers do not make the conceptualization and operationalisation of transitions explicit. Therefore, this aspect adds strength to the proposed scoping review.

It is important, however, to focus on all multiple transitions they will be experiencing at the same time and try to explore what other transitions have been (potentially implicitly) presented in the health literature you currently plan to review. These could, for instance, be developmental, educational, relationship transitions. This is important as their transitions to healthcare systems will trigger, and be triggered by, other transitions. This will also be the case for the families and professionals, with their transitions interacting with those of children and young people.

Although I understand this is outside the scope of the proposed review, I believe it will be useful for the authors to review conceptualisation and theoretical frameworks of transitions in other disciplines too. Also, it will be important to publish your scoping review beyond journals from a

particular discipline as there is a gap in this area.

**Is the rationale for, and objectives of, the study clearly described?**

Yes

**Is the study design appropriate for the research question?**

Yes

**Are sufficient details of the methods provided to allow replication by others?**

Yes

**Are the datasets clearly presented in a useable and accessible format?**

Yes

**Competing Interests:** No competing interests were disclosed.

**Reviewer Expertise:** Education, health education, educational and life transitions, systematic literature review, creativity, inclusion, voice

**I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.**

Reviewer Report 06 October 2020

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**Tim Rapley** 

Department of Social Work, Education and Community Wellbeing, Northumbria University, Newcastle upon Tyne, UK

This protocol outlines a scoping review on transition from child to adult healthcare services and systems for young people with neurodisability.

It is clear, accessible and well written and outlines the process in enough detail. The primary research question is timely as are the secondary focus (especially how transition is operationalized)

**Is the rationale for, and objectives of, the study clearly described?**

Yes

**Is the study design appropriate for the research question?**

Yes

**Are sufficient details of the methods provided to allow replication by others?**

Yes

**Are the datasets clearly presented in a useable and accessible format?**

Not applicable

**Competing Interests:** No competing interests were disclosed.

**Reviewer Expertise:** Health Services Research, Implementation, CYP

**I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.**

Author Response 19 Oct 2020

**Jennifer Fortune**, RCSI University of Medicine and Health Sciences, Dublin, Ireland

Thank you for reviewing our protocol. We appreciate your comments, particularly your feedback on our research question and secondary focus.

**Competing Interests:** No competing interests were disclosed.

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