

# BMJ Open Strategies and tools to aid the transition between paediatric and adult health services for young adults with neurodevelopmental disorders: a scoping review protocol

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## ABSTRACT

**Introduction** The transition from paediatric to adult healthcare comes with risk and vulnerability for young adults with neurodevelopmental disorders and their carers. Deficits in health, social and disability systems and the fragmentation of services exacerbate problems during the transition period, leaving young people and their carers feeling disconnected with existing services. With advances in healthcare, the number of young adults with neurodevelopmental disorders requiring transition services is increasing. This scoping review aims to summarise the strategies and tools that help ease the transition to adult services for young adults with neurodevelopmental disorders.

**Methods and analysis** Systematic searches of MEDLINE, EMBASE and PsychInfo on the OVID platform were performed on 28/05/2022. Studies that describe tools or strategies designed to ease the transition from child-centred to adult-orientated healthcare for young adults with neurodevelopmental disorders will be included. Two authors will independently review titles, abstracts and full-text articles against the inclusion criteria to determine eligibility. Data will be extracted and synthesised using descriptive stats and thematic analysis. The Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews guidelines will be followed.

**Conclusion** This scoping review will synthesise the published literature describing strategies and tools to improve the transition of young adults with neurodevelopmental disorders to adult services. The findings of the review may inform areas of future research to improve care for all involved in the transition process.

**Ethics and dissemination** This review will include published data; as such, ethics approval is not required. We will publish our findings in an open-access, peer-reviewed journal and summarise the results for dissemination to the wider community of clinicians, allied healthcare professionals, teaching professionals, policymakers, non-governmental organisations, impacted youth and parents.

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This study will provide a comprehensive overview of the published literature describing tools and strategies to improve the transition from paediatric to adult healthcare services for young adults with neurodevelopmental disorders.
- ⇒ We will consider how young adults with neurodevelopmental disorders and their carers have been included in the literature to ensure relevance for clinical practice.
- ⇒ A potential limitation in reviewing this work is that what is considered typical and atypical development continues to be re-evaluated, so defining terms is challenging.
- ⇒ Another limitation could be the limited number of articles that assess the efficacy of tools or strategies related to the transition from paediatric to adult healthcare services for young adults with neurodevelopmental disorders.

## INTRODUCTION

Neurodevelopmental disorders can be conceptualised in several ways. From a medical perspective, neurodevelopmental disorders are caused by disruptions within the central nervous system early in development and result in impairments in ambulation, information processing, self-regulation and/or communication.<sup>1</sup> The 5th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) defines neurodevelopmental disorders as ‘a group of conditions with onset in the developmental period...that produce impairments of personal, social, academic, or occupational functioning’. Within this broad category, there is debate about classifications. For example, the International Classification of Diseases 11 categories differ somewhat from DSM-5, and both categorisation models undergo regular review.<sup>2,3</sup> This complexity is



reflected in published literature (where definitions vary across studies)<sup>4,5</sup> as well as in the clinical context (where neurodevelopmental clinics may support children with different disorders). A summary of conditions included in DSM-5, ICD10 and ICD11 sections on neurodevelopmental disorders and our paediatric neurodevelopmental clinic is presented in online supplemental appendix 1. In this review, we use the DSM-5 definition when referring to neurodevelopmental disorders, expanded slightly to include the kinds of conditions seen in neurodevelopmental clinics.

Amid debate about separating discrete aetiological categories, there is also an understanding that neurodevelopmental disorders exist on 'continuums' or 'gradients', and that functional challenges may co-occur and change over time.<sup>6</sup> The tension between the fluid functional realities and more rigid diagnostic frameworks poses some challenges. For example, reporting the prevalence of neurodevelopmental disorders is complicated by the substantial overlap between conditions. A population-based study conducted in the UK in reported that autism spectrum disorder occurred in 22% of children with epilepsy and attention deficit hyperactivity disorder (ADHD) occurred in 33% of children with epilepsy and behavioural problems occurred in 80% of children with epilepsy.<sup>7</sup> Data from 2006 to 2008 indicate that 15% of children in the USA aged between 3 and 17 were affected by a neurodevelopmental disorder.<sup>8</sup> In 2016, the Global Burden of Disease data reported that the global prevalence of neurodevelopmental disorders was 8.4%.<sup>9</sup> Despite changing definitions, it is clear neurodevelopmental disorders are impacting many children.

Due to advances in medical technology and healthcare practices, it is estimated that up to 90% of children with chronic healthcare needs survive into adolescence and adulthood.<sup>10</sup> For young adults with neurodevelopmental disorders and their families, the transition to adolescent and adulthood can pose new challenges. From a developmental perspective, the transition to adulthood is an important stage of emotional, psychosocial and psychological development, and a time when considerations about independent living and vocational opportunities are front of mind. From a healthcare perspective, young adults move from paediatric to adult services, often severing lifelong connections and starting fresh with new healthcare providers. This review is focused on the healthcare side of the transition. From this medical perspective, we define transition in line with Rosen *et al* as 'the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-orientated health care systems'.<sup>11</sup> Transition services can therefore include any sources of support to better equip and guide young adults and their family, as they move between paediatric and adult services.<sup>12</sup>

The increase in the number of young adults with neurodevelopmental transitioning from child-centred to adult oriented healthcare services has highlighted gaps

in availability, and quality, of transition services. There are several known issues, including poor communication between paediatric and adult services, limited resources, lack of knowledge on transition practices among adult care practitioners, inadequate transition planning and fear of new healthcare systems among young adults that are all recurring barriers highlighted in the literature.<sup>12</sup> Due to systems currently not set up, young adults with neurodevelopmental disorders often face transition difficulties as they find themselves without professional support or a referral to an adult service. In the event they are referred, adult services are ill equipped to meet their needs. An audit of 495 young adults with ADHD in the UK reported that only 15% of young adults with ADHD make a transition.<sup>13,14</sup>

The long-term effects of substandard transition include an increased risk of preventable complications, inappropriate reliance on emergency health services, increased hospital admissions, poor long-term clinical outcomes, disrupted psychological well-being and generally decreased quality of life.<sup>13-15</sup> A cross-sectional analysis revealed that, compared with the general population, young adults aged 19-24 with neurodevelopmental disorders face up to 125 times increased likelihood of poor health, a decline in mental health and limited ability to perform routine activities of daily living.<sup>15</sup> Needs may also change during this time. For example, a large-scale study conducted in California found that those diagnosed with autism during childhood were significantly more likely to develop psychiatric conditions in adulthood than the control group.<sup>16</sup> The transition period is when practical needs should be re-evaluated, each young adult needs to be linked up with the relevant services available for them into adulthood, and the type of services available to adults needs to be expanded and refined to meet community needs.

With the move away from institutionalisation and medicalisation of neurodevelopmental disorders, wider health services play an integral role in supporting the paediatric community's health and well-being.<sup>17</sup> Paediatric services are often multidisciplinary and family-focused, offering formal and informal supports such as specialist doctors, integrated allied health support, links to education systems and community groups. In contrast, adult services are often siloed, and the patient is approached as an individual with less input from the family, who often remain the primary caregivers due to the nature of the disabilities.<sup>17</sup>

Responding to calls for action, there has been a recent surge in research about transition models, with a growing body of literature seeking to understand 'what works'. To date, the literature has identified the features of transition practices, the perspectives of professionals and experiences of young adults and their families with the transition process, including barriers faced.<sup>18-21</sup> Several reviews have explored transition among young adults with physical, mental health, endocrine, neurological and gastrointestinal conditions and quantified the effectiveness

of transition practices.<sup>15 17 22–28</sup> However, these findings may not apply to young adults with neurodevelopmental disorders, due to the complexity of the disorders and the increased risk of developing other serious health problems as they age.

Two recent reviews are focused specifically on neurodevelopmental disorders. Fortune *et al* have published a scoping review protocol describing their intent to map the evidence about how young adults with neurodevelopmental disorders transition between child and adult services.<sup>29</sup> This review will help frame crucial concepts in this field. They plan to expand on how ‘transition’ is defined in this literature, what conditions are targeted within the broad umbrella of neurodevelopmental disorders, and what theories or models are used to inform thinking about transitioning young adults into adult services. Another scoping review published in 2022 takes a different approach to a similar issue. Gardiner *et al* clarify the definitions and role of a patient navigator in connecting young adults with neurodevelopmental disorders and their families to support within the community. They capture a wide range of transitions rather than focusing on the transition from paediatric to adult services.<sup>30</sup>

This protocol is for a scoping review that aims to complement the work described above. We aim to provide a comprehensive overview of tools and strategies currently available to help transition young adults with neurodevelopmental disorders from paediatric to adult healthcare services. We expect this will range from standardised paperwork (including checklists to acquire impressions of abilities and challenges) to workforce allocation (including patient navigation roles as highlighted by Gardiner *et al*).<sup>30</sup> We addressed this broad aim through the following questions:

- ▶ What are the proposed tools and strategies that might help the transition between paediatric and adult health services for young adults with neurodevelopmental disorders?
- ▶ Were the tools or strategies collaboratively designed and implemented with the input from those impacted by neurodevelopmental disorders? Were ethnicity or cultural aspects of care considered in the design and implementation?
- ▶ Was the tool/strategy implemented and evaluated? If so, what can we learn from the results?

This practical inventory of existing tools and strategies is needed to establish current practices, identify knowledge gaps and develop new approaches that could improve transition practices and long-term outcomes for young adults with neurodevelopmental disorders.

## METHODS AND ANALYSIS

We have reported this protocol in accordance with the relevant sections of the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for

Scoping Reviews (PRISMA-ScR) guideline. The same guideline will be used to report the final review.<sup>31</sup>

### Definitions and eligibility criteria

For this scoping review, we will use the DSM-5 definition for neurodevelopmental disorders, with inclusion of specific conditions modified slightly to meet clinical needs (as summarised in online supplemental appendix 1. We will include central sensory disturbances and fetal alcohol syndrome. We will use the WHO definition of a ‘young adult’ as an individual between 10 and 24 years of age,<sup>10</sup> and the Society for Adolescent Health and Medicine’s definition for ‘transition’ as ‘the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-orientated health care systems’.<sup>11</sup> We consider ‘tools and strategies’ to include any active intervention to improve the transition from paediatric to adult healthcare services. Table 1 outlines the inclusion and exclusion criteria using the Population, Intervention, Comparison, Outcomes and Study framework.

### Search strategy

#### Peer-reviewed literature

After piloting search strategies, we worked with an information specialist (IG) to critique and refine our search in accordance with Peer Review of Electronic Search Strategies (PRESS) guidelines.<sup>32</sup> The information specialist created a search which includes terms to describe transitioning from paediatric to adult healthcare services and terms for neurodevelopmental disorders. We decided not to include terms for tools and strategies as there may be a possibility that we would miss studies that may be potentially relevant that used a methodology that was not included in our search terms. We cross-referenced between the draft and formal search results to ensure relevant keywords and MeSH terms were used in the formal search. We will run searches on MEDLINE (Ovid), Embase (Ovid) and PsychInfo (Ovid) from 1990 to the current date (online supplemental appendix 2). We ran a preliminary search without a date cut-off. Scanning from the earliest published work, it appeared that it was not until the 1990s that the term ‘transition’ was used in connection to common neurodevelopmental conditions like autism. We aligned our inclusion criteria with this observation. We will iteratively check the reference lists from included articles and relevant reviews adding any relevant resources not yet captured.

All the results from the search will be entered into Covidence ([www.covidence.org](http://www.covidence.org)) for screening. Covidence is a web-based primary screening and data extraction tool. Two authors will independently review each title and abstract and exclude those that do not meet the inclusion and exclusion criteria. If the reviewers disagree, the two reviewers will discuss and resolve. A third author will be consulted if two initial reviewers can find no resolution. The full text of the selected articles will then be reviewed, and two authors will independently vote to include or

**Table 1** Inclusion and exclusion criteria

PICOS component	Inclusion criteria	Exclusion criteria
Population	Resources targeting young adults with neurodevelopmental disorders.	Not directly related to neurodevelopmental disorders (eg, diabetes, cystic fibrosis).
	Resources targeting the transition from paediatric to adult-orientated healthcare systems.	Not related to transition from paediatric to adult health services (eg, transitions from inpatient to outpatient care).
Intervention	Resources which include discussion of a tool (eg, a checklist, or transitional paperwork) or strategy (eg, education, transition meetings/clinics, transition coordinator).	No mention of tool or strategy (eg, only describing the challenges faced).
	Resources specifically about transitions of service provision within healthcare systems.	Not about healthcare (eg, only about vocational training as youth enters the workforce).
Comparator	No restrictions based on whether the intervention was compared with an alternative.	
Outcome	No restrictions on outcome measure used.	
Study type	Types of resources included <ul style="list-style-type: none"> <li>▶ Peer reviewed resources.</li> <li>▶ Primary papers (reviews will have reference lists extracted).</li> <li>▶ Any type of primary paper.</li> </ul>	Types of resources excluded <ul style="list-style-type: none"> <li>▶ Review papers as unique entities.</li> <li>▶ Published before 1990.</li> </ul>

PICOS, Population, Intervention, Comparison, Outcomes and Study.

exclude the articles. Again, conflict resolution will be handled by discussion and a third reviewer if needed. A PRISMA flow diagram will be used to summarise the screening process. We will not track excluded resources, as with the peer reviewed literature.

### Research Timeline

The search took place on 28 May 2022, and data extraction is expected to begin on 20 November 2022 and finish on 20 March 2023.

### Data charting

We will chart data by study, pooling common transition tools and strategies in the data synthesis stage. A data extraction form will be developed in Covidence based on [table 2](#). The form will be piloted on five resources and required amendments agreed by consensus. Given the expected diversity of the included studies, data charting will be iterative throughout the review. The reviewers will discuss these amendments and the form amended at each stage where necessary. Changes to the data charting will be documented in the final report. Each included resource will be charted independently by at least two reviewers. Any conflicts between reviewers will be resolved by discussion, and a third reviewer will be consulted if necessary. A quality appraisal will not be performed to avoid erroneously communicating that some approaches have more value than others based on methodological approach.

### Patient and public involvement

This project stems from a wider initiative involving a Delphi panel involving patient and public contributors to create a skills-based checklist for young adults with neurodevelopmental disorders and, as such, is part of ongoing community engagement.

### Data items

Data extraction will closely follow our research questions, as described in [table 2](#).

### Data synthesis

We will use descriptive statistics for discrete categorical data. For interconnected, non-mutually exclusive data (potentially the approach, required staff and setting of proposed tools and strategies), we will explore connections with using network plots. Open-ended questions will be analysed using thematic analysis. A postpositivist approach is best suited to our research question because we are aiming to produce a practical summary of existing tools and strategies. Two authors will independently familiarise themselves with open-ended questions and generate codes. Codes will be discussed, and initial themes generated. Responses will then be grouped into these themes, with discrepancies resolved through discussion, and new theme refined (consistent with 'codebook' rather than 'reflexive' thematic analysis).<sup>33</sup> We plan to use flow charts to visualise the proportion of interventions that have been implemented and evaluated and highlight reported results. The data synthesis process will remain iterative, with further refinements expected once we have had the opportunity to examine the selected articles in relation to one another.

## DISCUSSION

The transition period from paediatric to adult services is particularly challenging for young adults with neurodevelopmental disorders. Given the growing population of young adults with neurodevelopmental disorders requiring transition to age-appropriate healthcare services, there is an increasing need to identify supports used during this transition period. Effective transition

**Table 2** Data extraction

General characteristics: What are the general characteristics of resources which describe options to improve transitions?	
	Year of publication
	Country: <i>If multinational use corresponding author affiliation</i>
	Condition: <i>Targeted neurodevelopmental condition</i>
	Definition of transition: <i>What did 'transition' mean to the authors of the paper?</i>
	Age of transition: <i>What ages did 'transition' mean to the authors of the paper?</i>
Question 1: Tools/strategies: What tools/strategies to improve the transitions have been described? <i>This section is to capture key ideas (if commentary) or the intervention trialled (if implemented) to cover a wide range of options which may aid in transitions.</i>	
	Summary of tools/strategies ( <i>Free text</i> ) <i>A broad summary about tools or intervention</i>
	<i>How do the tools/strategies cluster together into similar approaches (eg, education, paperwork, clinics, new staff)?</i>
	People Which groups of people need to provide time or resources for this tool/strategy to work? ( <i>Choose all that apply</i> )
	Setting Does the tool/strategy require a clinical environment to be implemented? ( <i>Yes/No</i> ) <i>Would this tool/strategy need things at a clinic? (eg, are there specific assessments done as part of this or could you imagine this happening at a community centre?)</i>
Question 2: Patient-centredness: Were tools/strategies collaboratively designed and implemented with the diverse patients who experience these transitions?	
	Were the tools or strategies collaboratively designed (codesigned) with those impacted by neurodevelopmental disorders? ( <i>yes/no</i> ) <i>If so, how? (free text)</i>
	Were ethnicity or cultural aspects of care considered in the design and implementation of these tools or strategies? ( <i>yes/no</i> ) <i>If so, how? (free text)</i>
Question 3: Implementation and evaluation: In cases where these tools or strategies are implemented, how effective were they in aiding transition?	
For part A, 'implementation' we will include only the subset of papers describing tools/strategies which were tried by at least a single participant	
For part B, 'evaluation', we will include only the subset which were both implemented (had at least on participant) and evaluated (included a comparison)	
<i>This section will not include and evaluation of bias or quality (as in a systematic review), but rather help to understand author insights and provide some guidance for options worth pursuing or not</i>	
Part A (Only studies for which the tool/strategy was implemented)	Study participants <i>Who is involved as participants? (select all that apply)</i>
	Participant age <i>If patients are the participants, what is the age range of these youth? (minimum to maximum in years)</i>
	Participant number <i>Use those who completed the study, if more than one group, include all</i>
	Authors reflections about tool/strategy ( <i>free text</i> ) <i>what worked, what did not, and what insights did they offer for improving services</i>

Continued

**Table 2** Continued

Part B (Only studies for which the tool/strategy was evaluated)	Was there a pre-post comparison (yes/no)
	Outcome #1 (pre-post): If yes, what was the outcome measure? (free text) Did the pre-post analysis with this outcome suggest the tool/strategy was effective? (yes, no, inconclusive)
	Allow for recording of up to five different pre/post outcomes
	Was there a parallel comparison? (yes/no)
	Outcome #1 (parallel): If yes, what was the comparison arm? (free text) If yes, what was the outcome measure? (free text) Did the parallel analysis with this outcome suggest the tool/strategy was effective? (yes, no, inconclusive)
	Allow for recording of up to five different parallel comparison outcomes
	Was there an evaluation without a comparator? (yes/no)
	If yes, what was the outcome measure? (free text) Did the evaluation suggest the tool/strategy was effective? (yes, no, inconclusive)
	Allow for recording of up to five different outcomes without comparators

ensures that young adults become empowered to take control of their care and well-being, and better overall long-term health outcomes achieved. As far as we are aware, there has been no previous synthesis of existing tools and strategies specifically designed for young adults with neurodevelopmental disorders to improve the transition between paediatric and adult services. This scoping review aims to provide a practical summary of existing interventions, which will be a valuable resource for improving clinical services. We believe the findings of this scoping review will be helpful to clinicians, researchers, allied healthcare professionals, policymakers, education supervisors and most importantly, transition aged-youth and their families as we collaborate to improve the healthcare experience and overall quality of life for young adults with neurodevelopmental disorders.

### Ethics and dissemination

This scoping review will only use published, and publicly accessible data, and as such, ethics approval is not required. The findings of this scoping review will be used in a Delphi panel currently being convened to create a skills-based checklist for the transition of young adults with neurodevelopmental disorders from the paediatric to the adult healthcare service in Aotearoa, New Zealand. We will also publish our findings in an open-access, peer-reviewed journal and develop an accessible summary of the results for dissemination to the broader community. This community includes clinicians, allied healthcare professionals, teaching professionals, policymakers, non-governmental organisations, impacted youth and parents. Data generated from this review will be made available on reasonable request.

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**Contributors** LMH and FL conceived the idea for the review. YT, FL and LMH drafted and revised the protocol with suggestions from JR and CM. IG constructed the search. YT, FL, LMH, JR, CM and IG were involved with the review and final approval of the manuscript.

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