

# Transitional Care Interventions for Youth With Disabilities: A Systematic Review

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abstract

**CONTEXT:** Transition from the pediatric to the adult health care system is a complex process that should include medical, psychosocial, educational, recreational, and vocational considerations.

**OBJECTIVE:** In this systematic review, we aim to synthesize the evidence on transitional care interventions (TCIs) to improve the quality of life (QoL) for adolescents and young adults with childhood-onset disabilities, including neurodevelopmental disorders.

**DATA SOURCES:** Four electronic databases (Medline, Embase, PsycINFO, and Cumulative Index to Nursing and Allied Health Literature) were searched.

**STUDY SELECTION:** In the included studies, researchers examined TCIs for adolescents and young adults (12–24 years of age) with childhood-onset disabilities. Studies were experimental, quasi-experimental, and observational studies published in the last 26 years.

**DATA EXTRACTION:** Two reviewers independently completed study screening, data extraction, and risk-of-bias assessment.

**RESULTS:** Fifty-two studies were included. Five studies reported on QoL, but statistically significant improvements were noted in only 1 of these studies. Significant improvements were also found in secondary outcomes including disability-related knowledge and transitional readiness. TCIs targeted patients, families and/or caregivers, and health care providers and exhibited great heterogeneity in their characteristics and components.

**LIMITATIONS:** Inconsistent reporting on interventions between studies hindered synthesis of the relationships between specific intervention characteristics and outcomes.

**CONCLUSIONS:** Although there is limited evidence on the impact of TCIs on the QoL for youth with childhood-onset disabilities, there is indication that they can be effective in improving patient and provider outcomes. The initiation of transition-focused care at an early age may contribute to improved long-term health outcomes in this population.



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Improvements in medical treatment have resulted in as many as 50% to 90% of children with congenital or acquired physical disabilities reaching adolescence and adulthood.<sup>1-6</sup> There is a corresponding increase in the number of youth and young adults with childhood-onset disabilities, including neurologic disorders, requiring transition to age-appropriate and developmentally appropriate adult health care services.

Transition from the pediatric to adult health care system is a multifaceted process.<sup>7,8</sup> Poor continuity of care can lead to poor health outcomes and decreased opportunities to participate in the community.<sup>6,9,10</sup> Without continuous and appropriate services, health concerns may remain undetected, putting transition-aged youth at further risk of developing preventable secondary physical and mental health complications and comorbidities.<sup>11</sup> This phenomenon can lead to increased use of health care services and an inappropriate dependence on emergency health services.<sup>12-14</sup> Population data have indicated that young adults between the ages of 19.0 and 26.9 with acquired brain injuries, cerebral palsy, and spina bifida visited physicians 11.5 times per year and were admitted to the hospital once every 6.8 years.<sup>15</sup> These results suggest that adolescents and young adults with complex disabling conditions from childhood have ongoing health issues that require frequent service; their hospital admission rate is 9 times that of the general population and few have a primary care physician.<sup>15</sup> Thus, a growing need to implement fiscally sustainable approaches to transition has recently been identified in the literature, with cost-effective transition expected to have a positive and far-reaching impact on the health care system.<sup>16</sup>

The transition process can be further complicated by the risk of additional

psychosocial difficulties (eg, anxiety disorders, depression).<sup>17-25</sup> In addition, finding appropriate specialist adult care providers and resources is challenging because many adult programs have narrow eligibility criteria that are focused on adults with recent-onset disabilities.<sup>12,26</sup> There is also a general lack of training related to aging with a childhood-onset disability among adult health care providers.<sup>4,27,28</sup> This results in a gap in appropriate care and a growing population of transition-aged youth with disabilities who are either significantly underserved or receive no care in the adult health care system.<sup>7</sup>

Despite the importance of ensuring the continuity of pediatric and adult care and the significant detrimental health outcomes related to poor transition, there is limited evidence on the most effective transitional care interventions (TCIs) for adolescents and young adults with childhood-onset disabilities. In a systematic review published by The Cochrane Collaboration in 2016, researchers examined transition interventions for adolescents with a wide range of chronic health conditions but did not focus on disabilities, and the review was limited to randomized controlled trials (RCTs), which contrasts with the current review.<sup>29</sup> Moreover, a guideline for transition from pediatric to adult health care for youth with special health care needs was developed in 2016.<sup>30</sup> However, it also was not focused on adolescents and young adults with childhood-onset disabilities (ie, key words only included “chronic health conditions” and “chronic illness”) and the authors used a limited range of research designs and publication years.<sup>30</sup> Other research has described the difficulty in drawing conclusions on TCIs due to variability in clinical diagnoses.<sup>31-36</sup> Although chronic health conditions can be physically disabling, transition preparation for

youth with disabilities may have different requirements altogether.<sup>37</sup>

In the current systematic review, we directly address the described evidence gaps related to TCIs for adolescents and young adults with childhood-onset neurologic disabilities (eg, acquired brain injury, cerebral palsy, spina bifida), including neurodevelopmental disorders (eg, attention-deficit/hyperactivity disorder, autism spectrum disorder, communication disorders, intellectual disabilities, motor disorders, specific learning disorders).<sup>38</sup> We maintain a focus on disabilities by excluding nonneurologic chronic conditions and include youth between 12 and 24 years of age as well as a range of study designs, further addressing the gaps identified in previous studies.<sup>29-37,39-45</sup> We additionally target those interventions that may improve quality of life (QoL) as defined by the World Health Organization, consistent with the recent recommendations of the International and Interdisciplinary Health Care Transition Research Consortium.<sup>46,47</sup> Our specific research objective of this systematic review is to determine the impact of TCIs on QoL and other transitional care outcomes in youth with childhood-onset disabilities.

## METHODS

This systematic review was registered with the International Prospective Register of Systematic Reviews (CRD42019137773) and drafted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement.<sup>48</sup>

### Eligibility Criteria

Inclusion criteria for the current review comprised (1) exposure to a TCI; (2) participants aged between 12 and 24 years and with childhood-onset neurologic disabilities, including neurodevelopmental disorders; (3) evaluation of QoL

(primary outcome) and/or transitional readiness, satisfaction, treatment adherence, disability-related knowledge, self-advocacy and management skills, improved documentation of transitional issues, unanticipated or adverse outcomes, and health care resource use and cost data (secondary outcomes); (4) experimental, quasi-experimental, or observational study type; (5) English-language publication; and (6) publication after 1993, when the transitional care literature emerged.<sup>49</sup> Exclusion criteria comprised (1) participants with nonneurologic chronic conditions (eg, type 1 diabetes, asthma, cancer, inflammatory bowel disease, juvenile idiopathic arthritis), and (2) conference abstracts or proceedings.

TICs included educational and training interventions delivered to health care providers, the adolescents or young adults, their families, or a combination of these stakeholders. They also included structural changes (eg, developing clinics) or changes to professional roles. Because of the need to examine TICs at as early as 12 years of age, eligible studies included participants in a broader range than the 15- to 24-year range used by the United Nations Educational, Scientific, and Cultural Organization in their definition of youth.<sup>45,50</sup>

### Search Strategy and Information Sources

Literature search strategies were developed by using subject headings and text words related to transitional care for adolescents and young adults with childhood-onset disabilities. Studies were identified by searching Medline, Embase, PsycINFO, and Cumulative Index to Nursing and Allied Health Literature (EBSCOhost). The online content of the International Journal of Integrated Care published from January 1993 to April through June of 2019 was also reviewed for relevant articles

published online only. The search strategy was designed and conducted by an experienced librarian (L.P.) with input from the investigators. The search was completed on May 30, 2019.

Search terms for TICs were derived from the previously described systematic review on TICs.<sup>29</sup> Search terms for childhood-onset disabilities, including neurodevelopmental disorders, were derived from a combination of search terms from a previous systematic review on vocational interventions for young adults with childhood-onset disabilities,<sup>51</sup> the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*,<sup>38</sup> the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition*,<sup>52</sup> and a Cochrane systematic review on neurodevelopmental disorders.<sup>53</sup> The search strategy for Medline can be found in the Supplemental Information. Additional articles were identified by scanning the reference lists of included studies. Experts in the field of disability and transitional care, including members of the research team (M.T.B., M.P., and A.T.) were consulted to ensure that all relevant data were obtained.

### Study Selection and Data Abstraction

Two reviewers (B.B.L. and J.Z.S.) performed title and abstract screening (ie, level 1 screening) independently. To determine final inclusion (ie, level 2 screening), the full texts of potentially relevant articles were subsequently acquired and screened (also independently and in duplicate). Reviewer conflicts at all stages of the review were resolved by a third reviewer experienced in the area of research (S.E.P.M.) or by using discussion to reach consensus.

Data abstracted from publications included study characteristics, participant characteristics, TCI characteristics, and outcome results. Data abstraction on the TICs was informed by the Template for

Intervention Description and Replication (TIDieR).<sup>54</sup>

### Risk-of-Bias Assessment

Two reviewers (B.B.L. and J.Z.S.) independently assessed the risk of bias of included studies. The version 2 of the Cochrane risk-of-bias tool for randomized trials (RoB 2) was used to appraise RCTs.<sup>55</sup> To appraise nonrandomized and observational studies, the Risk Of Bias in Non-randomized Studies - of Interventions (ROBINS-I) tool was applied.<sup>56</sup> For each included study, reviewers evaluated individual domains within the respective tool used and assigned an overall risk-of-bias judgement.

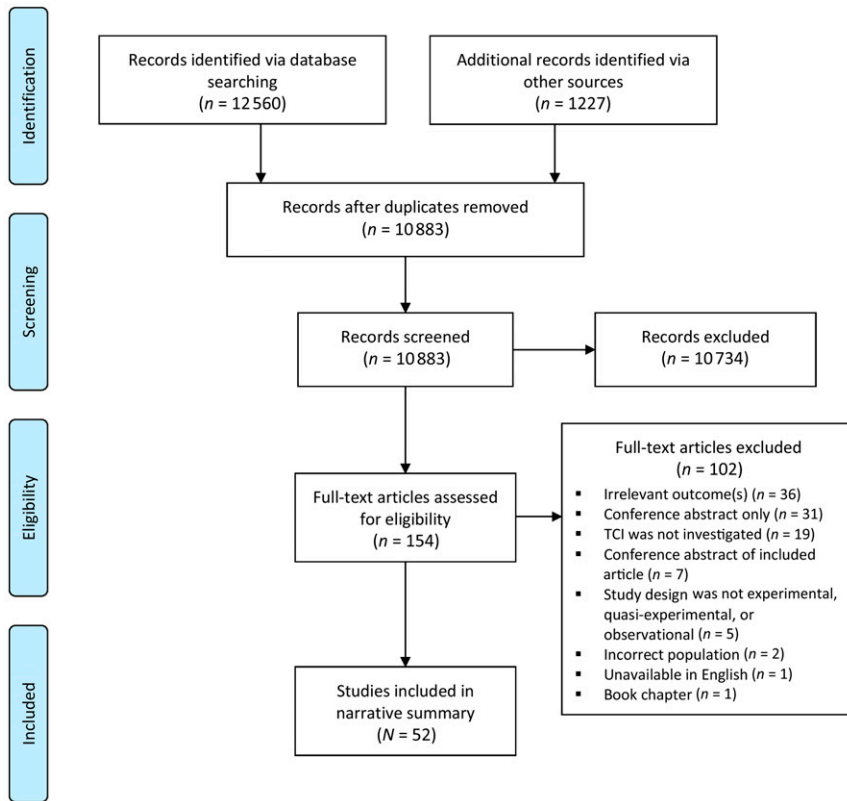
## RESULTS

### Study Selection

The literature search identified 13 787 records. Fifty-two studies remained for inclusion in the narrative summary. The systematic review process is outlined by using a Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram in Fig 1.

### Study Characteristics

Publication years of the included studies ranged between 1999 and 2019. Study types included prospective cohort ( $n = 23$ ), cross-sectional ( $n = 15$ ), RCT ( $n = 9$ ), and quasi-experimental studies ( $n = 5$ ). Recruitment settings included (specialized) clinics, the community, health care centers, hospitals, high schools and school districts, community colleges, and universities. Authors of included studies reported on a range of patient and provider outcomes from the perspective(s) of the patient, his or her family, and/or health care providers. In studies in which authors examined patient outcomes, patients' mean ages ranged from 14.8 to 26.8 years. Whereas the majority of studies (63%) which specified the percentage of female participants had <50% female



**FIGURE 1** Identified studies from the literature search and screening process. Adapted from Moher D, Liberati A, Tetzlaff J, Altman DG; PRISMA Group. Preferred Reporting Items for Systematic Reviews and Meta-Analyses: the PRISMA statement. *BMJ*. 2009;339:334.

participants, one study on autism spectrum disorder used 93% female participants, which is inconsistent with this disorder's higher prevalence in male patients.<sup>57</sup> Study sample sizes ranged from 8 to 1429 participants.

Conditions investigated included acquired brain injury, autism spectrum disorder, Asperger syndrome, Angelman syndrome, blindness, epilepsy, Down syndrome, hearing impairment, intellectual disability, neurodegenerative disease, neuromuscular disorders, osteogenesis imperfecta, spina bifida, and traumatic brain injury. The main characteristics of each included study are reported in Supplemental Table 1.

### Intervention Characteristics

TCIs in the included studies targeted patients, caregivers, and health care providers. Patient- and caregiver-

targeted interventions generally aimed to enhance the transitional readiness, disability-related knowledge, and self-advocacy and management skills of patients and/or their caregivers. This included the use of guided transition appointments at specialized clinics<sup>58–65</sup>; creation of curricula, informational materials, and/or health care information templates<sup>45,57,66–76</sup>; development of goals or of a specific transition plan<sup>39,77–85</sup>; and practical interventions on successful community living, including employment.<sup>86–91</sup> Some interventions combined several of the aforementioned approaches.<sup>92–96</sup> Provider-targeted interventions sought to increase health care providers' competence in providing effective transitional care by building their confidence, interest, and sensitivity and to enhance

workflow.<sup>57,97</sup> These interventions also aimed to enhance disability-related knowledge. Of the final 52 interventions, 33 were categorized as transition process interventions (ie, self-management programs and resources for community living), and 19 were categorized as act of transfer interventions (ie, occurring in and around clinics).

In the majority of studies (65%), authors cited, at minimum, one theory or theoretical foundation that informed the development and/or use of the intervention used. Such frameworks included models for the conceptualization, design, and/or implementation of the intervention,<sup>79,88,98</sup> support from the literature for decisions regarding the curriculum administered to participants,<sup>86</sup> and the use of relevant concepts in psychology (eg, social cognitive theory).<sup>57,66</sup> The TCIs used in each of the included studies are summarized in Supplemental Table 2 by using the TIDieR.

### Impact of TCIs on Patient QoL (Primary Outcome)

QoL data were reported in 5 studies.<sup>58,70,73,80,99</sup> The outcome was assessed by using a Likert-type scale (ie, nonvalidated, self-reported ratings), the DISABKIDS condition-generic module questionnaire,<sup>100</sup> the San Martín Scale for QoL,<sup>101</sup> the Personal Wellbeing Index–School Children,<sup>102</sup> and the QoL Questionnaire, abridged version.<sup>73</sup>

Significant improvements in postintervention QoL were noted only in a single study of 18 participants whose disabilities included autism spectrum disorder, hydrocephalus, Down syndrome, and intellectual disabilities. These improvements applied to subscales of the QoL measure only, rather than overall QoL.<sup>80</sup> Compared with the control group, significant improvements for the behavioral intervention group in the study were observed in the material well-being and personal

development subscales of the San Martín Scale for QoL ( $P < .05$ ).<sup>80</sup> The overall QoL in this study increased from 230.9 (SD = 24.6) to 259.5 (SD = 17.5) from preintervention to postintervention; however, this score dropped to 204.0 (SD = 43.0) 6 weeks after completion of the intervention.<sup>80</sup> Cramm et al,<sup>99</sup> Hatfield et al,<sup>70</sup> and Nadig et al<sup>73</sup> did not find any significant changes in QoL after participation in TCIs. However, Cramm et al<sup>99</sup> did note significant relationships between satisfaction with transitional care preintervention and emotional and physical QoL postintervention ( $P \leq .05$ ) and between satisfaction with transitional care postintervention and emotional, physical, and social QoL postintervention ( $P \leq .001$ ). In the study by Aguilera et al,<sup>58</sup> the majority of study participants (70%) reported their QoL to be “excellent” or “very good” after participating in the intervention. Because of infrequent reporting of concurrent intellectual disability, we were unable to draw conclusions between the presence of intellectual disability and outcomes.

### Impact of TCIs on Patient Secondary Outcomes

Of the aforementioned secondary outcomes, the highest proportion of patient-focused studies reported on self-advocacy and management skills ( $n = 19$ ), satisfaction ( $n = 18$ ), and transitional readiness ( $n = 15$ ). In several patient-focused studies, authors also reported on disability-related knowledge ( $n = 4$ ), documentation of transitional issues ( $n = 1$ ), and health care resource use ( $n = 2$ ).

Of the studies which reported on self-advocacy and management skills, the majority (58%) found statistically significant improvements after the administration of a TCI. Significant improvements in patient satisfaction were observed in only 5 of 18 studies, but in most studies that did not reach statistical significance for this

outcome, authors still noted increases in patient satisfaction after the intervention. In only 4 of 15 studies, authors reported statistically significant improvements in transitional readiness postintervention as measured by instruments such as the Rotterdam Transition Profile and Mind the Gap scale.<sup>45,90,103,104</sup> However, similar to the patient satisfaction outcome, in several studies, authors reported improvements in transitional readiness but did not include statistical analysis of these findings.

Statistically significant improvements in disability-related knowledge were found in all 4 studies that reported on this outcome. In the study that reported on documentation of transitional issues for patients, a significant improvement in the documentation of goals was shown postintervention.<sup>95</sup> In 2 studies, authors examined health care resource use, but changes in this outcome (eg, additional costs, cost savings) were not determined because of an absence of comparators.<sup>58,105</sup> Patient-related secondary outcome data are detailed in Supplemental Table 3 for 46 studies. Including both the primary and secondary outcomes of the current review, 12 studies in total used parent-proxy reports. Caregiver-related outcome data are detailed in Supplemental Table 4 for 6 studies.

### Impact of TCIs on Health Care Provider Outcomes

Studies reported on self-advocacy and management skills ( $n = 1$ ), satisfaction ( $n = 3$ ), and transitional readiness ( $n = 3$ ) outcomes for providers of interventions. Studies also reported on disability-related knowledge ( $n = 2$ ) and documentation of transitional issues ( $n = 1$ ), both as provider-specific outcomes. Provider-related outcome data are outlined in Supplemental Table 5 for 7 studies.

### Risk-of-Bias Assessment

Of the overall study assessments conducted by using the ROBINS-I tool ( $n = 43$ ), the majority of studies (53%) were judged to have a low risk of bias, 40% were judged to have a moderate risk of bias, and 7% were judged to have a serious risk of bias. Nine RCTs were assessed by using RoB 2. Two of these studies received a low overall risk-of-bias rating,<sup>73,76</sup> 6 received a “some concerns” rating,<sup>39,57,74,77,95,106</sup> and 1 received a high overall risk-of-bias rating.<sup>82</sup> Risk-of-bias data are summarized in Supplemental Tables 6 and 7.

### DISCUSSION

Our objective of this systematic review was to evaluate the effectiveness of TCIs on the QoL and transitional care outcomes of adolescents and young adults with childhood-onset disabilities. Included studies ( $n = 52$ ) reported on a broad range of disabilities including acquired brain injury, cerebral palsy, and spina bifida and generally observed improvements in QoL, disability-related knowledge, documentation of transitional issues, satisfaction, self-advocacy and management skills, and transitional readiness. However, evidence on the primary outcome of the current review, QoL, was limited to 5 studies only. Of these studies, only 1 reported significant improvements in QoL and only in specific subscales of the outcome measure.<sup>80</sup> Because QoL is highly important to consider in the evaluation of TCIs,<sup>46</sup> its incorporation as a measured outcome in future studies is warranted given our results. Careful conceptual consideration of QoL and its related outcomes is also advised because there may be immediate outcomes associated with transitional care that elicit demonstrable QoL gains; however, more distal QoL outcomes may be elicited over time (because transitional care may reflect youth

adjustment and ultimate engagement in ongoing care). The maintenance of QoL throughout the transition process may also be a positive result given the multifactorial nature of QoL, the large number of existing outcome measures, and the differing foci of these measures. Elucidating the impacts of interventions on specific QoL dimensions and developing more focused goals that account for factors such as aging caregivers and functional decline may lead to more feasible recommendations for the long term. Empirical and conceptual developments of the link between transitional care and QoL outcomes are encouraged, as are measures with specific applicability to notions of transitional care.

Statistically and clinically significant outcomes were not observed at the follow-up time point(s) for several studies (ie, there was a decline in measured outcome[s] between the completion of the intervention and the follow-up period[s]). Hall<sup>80</sup> reported significant improvements in the self-determination, material well-being, personal development, social inclusion, and interpersonal relationships subscales of the QoL measure immediately after intervention completion, yet the majority (60%) of these improvements lost statistical significance at the final post-test after only 6 weeks. This pattern is also reflected in the study by Healy and Rigby,<sup>89</sup> as decreases in composite performance scores for transitional readiness between the end of the program and follow-up (4 months later) were noted in 60% of participants. These declines in outcomes within the relatively short periods between intervention completion and follow-up suggest that methods of increasing the long-term effectiveness of transitional care should be investigated in future studies and prioritized for future interventions. Similarly, in a recent review of systematic reviews on

youth-focused transition interventions, Hart et al<sup>107</sup> found that only 14 of 71 studies were focused on the phase of transition that occurs after transfer to adult care. This gap in the literature is underscored by the findings of the current review, particularly for studies in which authors focused on the act of transfer between clinics. The difficulty of reporting on this third (ie, post-transfer) phase of transition has been noted in the literature and may be due to late completion of transfer (eg, at 25 or 26 years of age) for which research funding over an extended period may be both expensive and unlikely.<sup>78</sup>

Authors of several studies did report statistical significance being maintained at the follow-up time point.<sup>93,94,104</sup> For example, Kramer et al<sup>93</sup> reported an increase in knowledge of the physical and social environment, strategies to change the environment, and disability rights laws after completion of the intervention and at 6-week follow-up. However, the magnitude of the mean score on the outcome scale used decreased between intervention completion and follow-up. Of the studies that included parent-proxy reports, several also included youth reports and/or made comparisons between the 2 reporting types.<sup>59,62,68,70,85,93</sup> Hatfield et al<sup>70</sup> found a significant improvement in transition-specific self-determination based on parent-proxy reports but not youth reports. In contrast, Kramer et al<sup>93</sup> did not find significant improvement in self-determination based on either parent-proxy or youth reports. Given the small number of studies featuring both reporting types and the variability in conclusions even with the same outcome being assessed, it is difficult to determine the impact of parent-proxy reporting on outcomes (ie, if outcomes are improved, hindered, or stay the same).

In several studies, authors described interventions that were adapted by patients and their family members. For example, in the Youth Transition Demonstration Project, Croke and Thompson<sup>87</sup> changed the types of services offered to families on the basis of their specific needs, availability, and interests. This approach may be useful as a method of increasing participation and improving outcomes, particularly if the adolescents and/or young adults are themselves responsible for the decision-making. The use of patient experience to guide the implementation of interventions (eg, by asking patients about factors such as health, mobility, and QoL) has been suggested.<sup>108</sup> It is important to note that although youth and their parents may share some beliefs around transition, they may also have different expectations.<sup>109</sup> There is also a need for interventions to account for developmental appropriateness by evolving with participants and being responsive to the developmental needs of patients. Although several interventions that included youth in their early adolescence (ie, 12–15 years of age) incorporated individualized plans or needs assessments as intervention components, most interventions did not discuss the use of a developmental approach and instead focused specifically on the peritransfer period. The Shared Management Model used in the study by Kingsnorth et al<sup>71</sup> promotes a gradual shift in health care expectations and responsibilities from health care professionals, to parents, to youth that is based on developmental appropriateness. Considering the developmental phases of youth during the design and implementation of interventions may promote better and more sustainable long-term outcomes. By assessing patients' progress educationally, socially, and vocationally, interventions can effectively address

a range of developmental milestones and transitions. Short-term interventions may have difficulty addressing the changing needs of youth in this manner, conceivably hindering their sustainability compared to long-term interventions. The role of the caregiver is also of importance because caregiver involvement is often determined by the developmental phase of patients. Colver et al<sup>103</sup> have found that ensuring an optimal level of parent involvement can result in better outcomes for youth with autism spectrum disorder and cerebral palsy. Increased parental satisfaction with their own involvement in the transition process has also been associated with reports of an easier transition by youth.<sup>110</sup> However, appropriate parent involvement can differ between individuals and may depend on factors such as chronological age, developmental milestones, and the individual needs and concerns of youth.

Despite the decision to expand the age range used for youth by the United Nations Educational, Scientific, and Cultural Organization to begin at 12 years of age (from 15 years of age) for study inclusion, only 2 studies had a mean age of participants <15 years old.<sup>68,70</sup> The recent publication dates of studies that include youth in their early adolescence (ie, 12–15 years of age) may be indicative of a more recent trend of starting transition-focused care at a younger age. It is conceivable that the initiation of transition discussion and interventions at an early age may contribute to long-term outcome improvements, in part because of increased comfort, familiarity, and expectations with the transition process.

This systematic review is supported by several major strengths, including the completion of screening, data extraction, and quality appraisal by 2 reviewers independently and in duplicate. The broad scope of the review, particularly the inclusion of all forms of transitional care, regardless of specific intervention characteristics, is of benefit given the heterogeneity of the interventions used. A broad range of childhood-onset disabilities, including neurodevelopmental disorders, was also included. The inclusion of multiple study types further aided the incorporation of additional relevant outcome data into the synthesis. The relatively large publication year range included in the literature search, corresponding to the emergence of transitional care in the literature, also contributed to the comprehensive nature of the findings.<sup>49</sup> This review additionally benefitted from the use of an experienced librarian (L.P.) to conduct the literature search.

Several limitations are also acknowledged. In the majority of studies (90%), authors did not report on at least 3 of the 12 items in the TIDieR checklist.<sup>54</sup> Although some authors provided additional information on their intervention once contacted, the inconsistent reporting on interventions between studies limited our synthesis of the relationships between specific intervention characteristics and outcomes. On the basis of the inclusion of only 9 RCTs and the heterogeneity of RCT-specific outcome measures, it was also not feasible to conduct a meta-analysis. Because of the exclusion of non-English studies, there was bias toward English-speaking countries. Lastly, the decision to exclude conference abstracts may have

introduced publication bias; however, we were unable to compare the studies associated with conference abstracts to the studies associated with full articles.<sup>111</sup>

## CONCLUSIONS

In this systematic review on TCIs for adolescents and young adults with childhood-onset disabilities, we found limited evidence on the impact of TCIs on QoL for adolescents and young adults with childhood-onset disabilities. Secondary outcomes of the current review did reveal some statistically significant improvements after administration of TCIs. Given the loss of several statistically and clinically significant outcomes at follow-up time points, future interventions should prioritize methods of increasing the long-term efficacy of transitional care and improved means for impact measurement. The initiation of transitional care at an early age and/or continuation of interventions into adulthood could contribute to long-term outcome improvements; however, further examination and methodologic precision may be needed to fully ascertain this impact.

## ABBREVIATIONS

QoL: quality of life  
RCT: randomized controlled trial  
RoB 2: version 2 of the Cochrane risk-of-bias tool for randomized trials  
ROBINS-I: Risk Of Bias in Non-randomized Studies - of Interventions  
TCI: transitional care intervention  
TIDieR: Template for Intervention Description and Replication

Mr Levy conducted data acquisition and data analysis and drafted the initial manuscript; Ms Song conducted data acquisition and data analysis; Dr Perrier conceptualized and designed the study and conducted data acquisition and data analysis; Drs Bayley, Andrew, Arbour-Nicitopoulos, Chan, Dimitropoulos, Hartman, Huang, Kastner, Kingsnorth, McCormick, Nelson, Nicholas, Penner, and Toulany and Ms Luong, Ms Curran, Ms Thompson, Ms Woo, and Ms Zee conceptualized and designed the study and contributed to data analysis and data interpretation; Dr Munce conceptualized and designed the study and supervised the data acquisition and data analysis; and all authors reviewed and revised the manuscript critically for important intellectual content, approved the final manuscript as submitted, and agree to be accountable for all aspects of the work.

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