

Improving Transition to Adult Care for Those With Developmental Disabilities: An Unclear Path

Laura C. Hart, MD, MPH

In this issue of *Pediatrics*, Levy et al¹ present a systematic review focused on the transition from pediatric to adult care for adolescents and young adults with neurodevelopmental disabilities. The transition from pediatric to adult health care is a challenge for patients with neurodevelopmental disabilities and their families.²⁻⁴ Patients are not only changing from pediatric to adult health systems but also working on such things as getting the appropriate educational supports in college, applying for disability (if appropriate), or finding services for adults to replace the support services provided in the school setting. With this review, Levy et al¹ sought to identify those interventions that providers and systems can use to support families during this difficult process, ultimately concluding that although interventions may help with transition readiness and patient disease knowledge, the data are limited, especially with respect to patient quality of life, the primary outcome of interest in this review.

The review by Levy et al¹ is notable for its expansive consideration of transition interventions. The interventions themselves could consist of a specialized transition clinic, educational materials, a formal transition curriculum, or transition plan development, alone or in combination. The target could be patients, families, and/or providers. The interventions were done in a variety of settings, including high schools, colleges, community settings,

and health care settings (clinics and hospitals). Their choice to consider transition in such a broad way resulted in the inclusion of a wide range of studies not considered in other systematic reviews on the topic. This review does not just update the evidence base with recently published studies; it challenges us as health care providers to consider transition beyond the health care space, just as the patients and families whom we take care of have to do. Unfortunately, even with a more expansive consideration, this systematic review is in agreement with others, in that we still do not know what works for transition.⁵⁻⁸

Nearly every commentary on transition concludes with a call for more research, and this commentary will be no different. The review by Levy et al¹ underscores the need not only for more transition research but also for more rigor in the research conducted in the field.

One of the key gaps in improving research on transition is related to measuring transition success. This measurement concern is well recognized; it goes back over 25 years. In its first position statement on transition, the Society for Adolescent Medicine (now the Society for Adolescent Health and Medicine) asked, "What are the most appropriate outcome measures for evaluative [transition] research?"⁹ Today, we still do not have an answer. Improved measurement for transition is a scientific priority in the *Eunice*

Primary Care Pediatrics, Nationwide Children's Hospital and Department of Pediatrics, College of Medicine, The Ohio State University, Columbus, Ohio

Opinions expressed in these commentaries are those of the author and not necessarily those of the American Academy of Pediatrics or its Committees.

DOI: <https://doi.org/10.1542/peds.2020-024398>

Accepted for publication Aug 7, 2020

Address correspondence to Laura C. Hart, MD, MPH, Nationwide Children's Hospital, 700 Children's Drive, Columbus, OH 43205. E-mail: laura.hart@nationwidechildrens.org

PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

Copyright © 2020 by the American Academy of Pediatrics

FINANCIAL DISCLOSURE: The author has indicated she has no financial relationships relevant to this article to disclose.

FUNDING: No external funding.

POTENTIAL CONFLICT OF INTEREST: The author has indicated she has no potential conflicts of interest to disclose.

COMPANION PAPER: A companion to this article can be found online at www.pediatrics.org/cgi/doi/10.1542/peds.2020-0187.

To cite: Hart LC. Improving Transition to Adult Care for Those With Developmental Disabilities: An Unclear Path. *Pediatrics*. 2020;146(5):e2020024398

Kennedy Shriver National Institute of Child Health and Development 2020–2024 strategic plan.¹⁰

Transition research will be greatly improved by the consistent use of reliable, relevant, and feasible measures that are valid across the whole transition age spectrum, from 12 to 26 years. The science of measurement is often not compelling to those of us interested in implementing critically needed interventions, but without good measures, it will not be possible to really know what is successful.

Transition research would also be enhanced by improved conduct and reporting of trials of transition interventions. Levy et al¹ carefully describe the risk of bias across the studies included in their review and found moderate to high risk of bias in most of their included articles. To improve the process of transition, we must understand how we can build on the body of work to improve study rigor. Beyond improving measurement, there are opportunities to engage in a breadth of recruitment strategies to ensure that participants are representative of the population of interest, such as employing a range of methods used in other fields to minimize loss to follow-up and missing data^{11,12} and thoroughly describing the timing and duration of interventions so that total exposure to particular interventions can be accurately compared across studies.

The studies involving transition interventions have often been time limited and focused on the period just before the actual transfer to adult care, which Levy et al¹ noted in their review. Although the time just before leaving pediatrics is an important one in the transition process, transition guidelines currently recommend beginning the transition process in early adolescence and continuing well after the handoff to an adult provider to ensure that the patient and family are

settled into adult care.¹³ In other words, transition is not just the time from the last pediatric visit to the first adult visit. It should be a deliberate process that happens over years, not months. If transitional care spans years, so should transitional care research. In particular, and as Levy et al¹ note in the review, more studies need to consider the early and late stages of transition.

The challenges of transition are well documented. The solutions are not clear yet. I look forward to a day when the evidence is clearer. With reliable and valid measures being used in robust longitudinal trials, I think we can get there, and then we can use that science to improve transition for all the adolescents and young adults facing this daunting challenge.

REFERENCES

1. Levy BB, Song JZ, Luong D, et al. Transitional care interventions for youth with disabilities: a systematic review. *Pediatrics*. 2020;146(5):e20200187
2. Bindels-de Heus KG, van Staa A, van Vliet I, Ewals FV, Hilberink SR. Transferring young people with profound intellectual and multiple disabilities from pediatric to adult medical care: parents' experiences and recommendations. *Intellect Dev Disabil*. 2013;51(3):176–189
3. Cheak-Zamora NC, Teti M. "You think it's hard now ... It gets much harder for our children": youth with autism and their caregiver's perspectives of health care transition services. *Autism*. 2015;19(8):992–1001
4. Stewart D, Law M, Young NL, et al. Complexities during transitions to adulthood for youth with disabilities: person-environment interactions. *Disabil Rehabil*. 2014;36(23):1998–2004
5. Hart LC, Patel-Nguyen SV, Merkley MG, Jonas DE. An evidence map for interventions addressing transition from pediatric to adult care: a systematic review of systematic reviews. *J Pediatr Nurs*. 2019;48:18–34
6. O'Hara MC, Hynes L, O'Donnell M, et al; Irish Type 1 Diabetes Young Adult Study Group. A systematic review of interventions to improve outcomes for young adults with type 1 diabetes. *Diabet Med*. 2017;34(6):753–769
7. Embrett MG, Randall GE, Longo CJ, Nguyen T, Mulvale G. Effectiveness of health system services and programs for youth to adult transitions in mental health care: a systematic review of academic literature. *Adm Policy Ment Health*. 2016;43(2):259–269
8. Coyne I, Sheehan AM, Heery E, While AE. Improving transition to adult healthcare for young people with cystic fibrosis: a systematic review. *J Child Health Care*. 2017;21(3):312–330
9. 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):570–576
10. Eunice Kennedy Shriver National Institute of Child Health and Human Development. *NICHD Strategic Plan 2020*. Bethesda, MD: National Institutes of Health; 2019
11. Mercieca-Bebber R, King MT, Calvert MJ, Stockler MR, Friedlander M. The importance of patient-reported outcomes in clinical trials and strategies for future optimization. *Patient Relat Outcome Meas*. 2018;9:353–367
12. Teague S, Youssef GJ, Macdonald JA, et al; SEED Lifecourse Sciences Theme. Retention strategies in longitudinal cohort studies: a systematic review and meta-analysis. *BMC Med Res Methodol*. 2018;18(1):151
13. White PH, Cooley WC; Transitions Clinical Report Authoring Group; American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians. Supporting the health care transition from adolescence to adulthood in the medical home. [published correction appears in *Pediatrics*. 2019;143(2):e20183610]. *Pediatrics*. 2018;142(5):e20182587

Improving Transition to Adult Care for Those With Developmental Disabilities: An Unclear Path

Laura C. Hart

Pediatrics originally published online October 12, 2020;

Updated Information & Services	including high resolution figures, can be found at: http://pediatrics.aappublications.org/content/early/2020/10/08/peds.2020-024398
References	This article cites 12 articles, 2 of which you can access for free at: http://pediatrics.aappublications.org/content/early/2020/10/08/peds.2020-024398#BIBL
Permissions & Licensing	Information about reproducing this article in parts (figures, tables) or in its entirety can be found online at: http://www.aappublications.org/site/misc/Permissions.xhtml
Reprints	Information about ordering reprints can be found online: http://www.aappublications.org/site/misc/reprints.xhtml

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN®



PEDIATRICS®

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

Improving Transition to Adult Care for Those With Developmental Disabilities: An Unclear Path

Laura C. Hart

Pediatrics originally published online October 12, 2020;

The online version of this article, along with updated information and services, is
located on the World Wide Web at:

<http://pediatrics.aappublications.org/content/early/2020/10/08/peds.2020-024398>

Pediatrics is the official journal of the American Academy of Pediatrics. A monthly publication, it has been published continuously since 1948. Pediatrics is owned, published, and trademarked by the American Academy of Pediatrics, 345 Park Avenue, Itasca, Illinois, 60143. Copyright © 2020 by the American Academy of Pediatrics. All rights reserved. Print ISSN: 1073-0397.

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN®

