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Transitioning from Pediatric to Adult Healthcare

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- I have no relevant financial relationships with the manufacturer(s) of any commercial product(s) and/or provider(s) of commercial services discussed.

Objectives

- Describe current status of transition for youth with special healthcare needs and youth with developmental disabilities
- Understand barriers to transition from pediatric to adult healthcare
- Identify best practice guidelines for transition from pediatric to adult healthcare
- Initiate discussion and contemplation of shared decision-making options
- Discuss practical strategies to help prepare for transition

Transition to Adulthood

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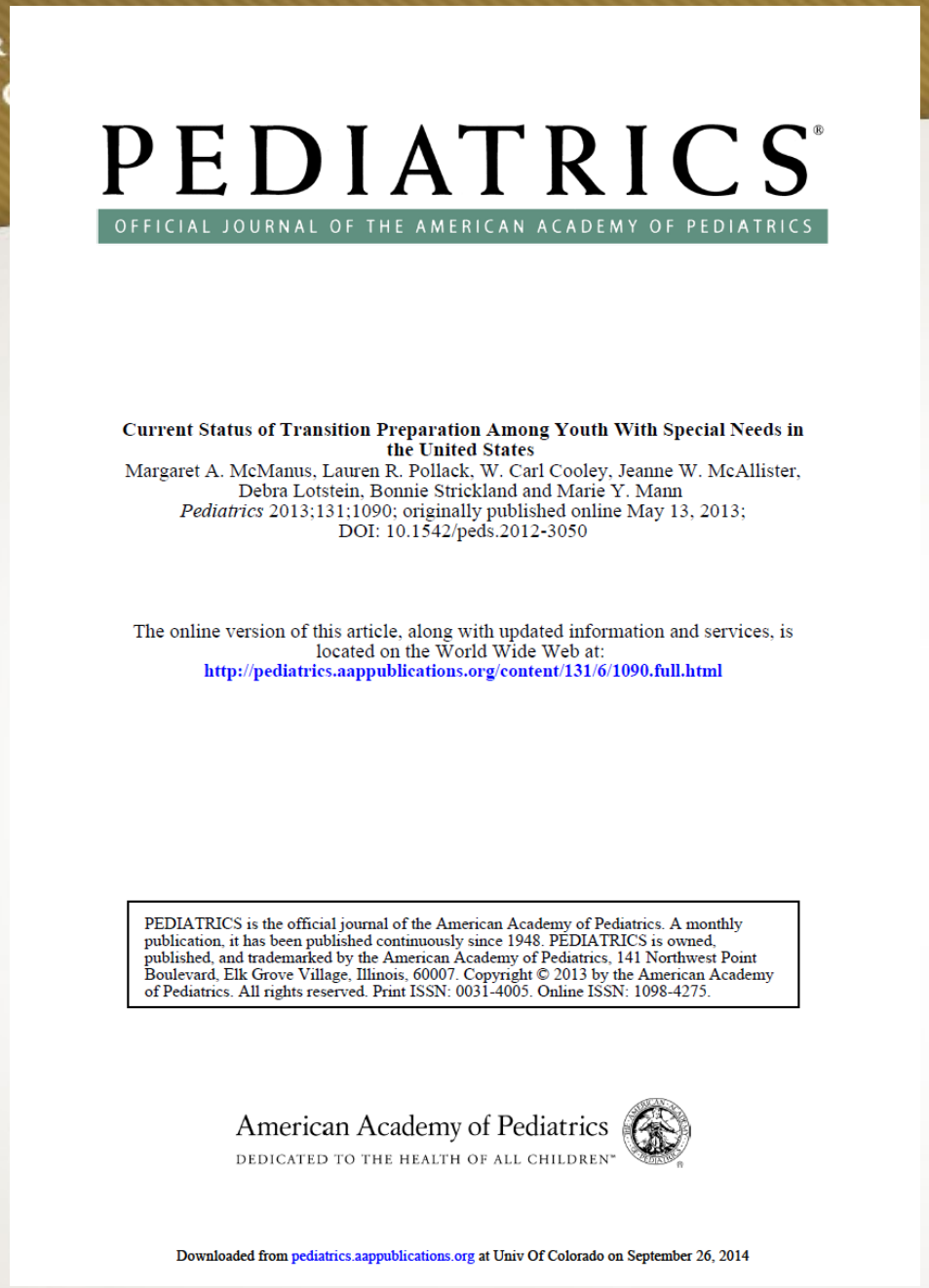

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Current Status of Transition Preparation Among Youth With Special Needs in the United States

Margaret A. McManus, Lauren R. Pollack, W. Carl Cooley, Jeanne W. McAllister, Debra Lotstein, Bonnie Strickland and Marie Y. Mann

Pediatrics 2013;131;1090; originally published online May 13, 2013;
DOI: 10.1542/peds.2012-3050

- ~40% of YSPHCN undergo successful transition
  - Youth with IDD less likely

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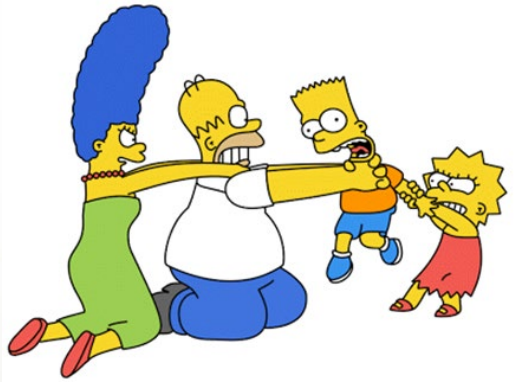
Barriers to transition



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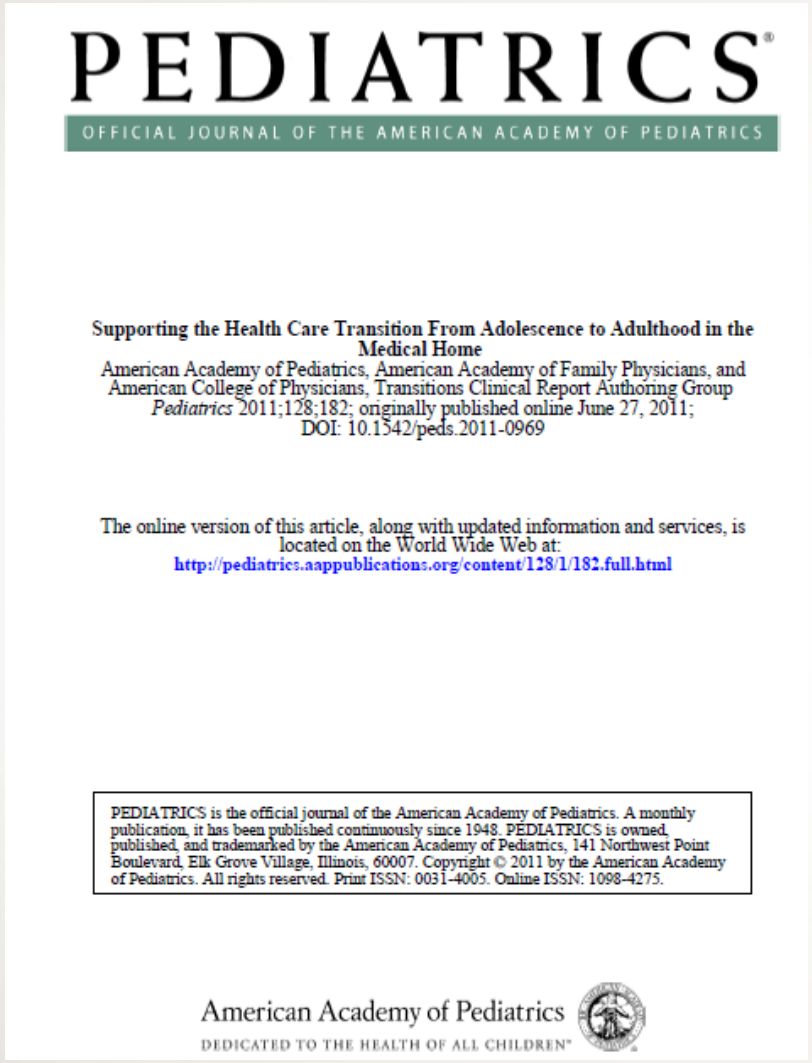
Transition Guidelines



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Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home

American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians, Transitions Clinical Report Authoring Group

Pediatrics 2011;128;182; originally published online June 27, 2011;
DOI: 10.1542/peds.2011-0969

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/128/1/182.full.html

American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN™

- 2011 AAP recommendations
  - Transition algorithm for provided primary care

Got Transition 2.0 Toolkit

- Toolkit created by The National Alliance to Advance Adolescent Health.
- 6 core elements of transition:
  - 1. Transition Policy
  - 2. Transition Tracking/Monitoring
  - 3. Transition Readiness Assessment
  - 4. Transition Planning
  - 5. Transfer of Care
  - 6. Transfer Completion

Got Transition Steps for Adolescents and Families

- Following steps outlined at: https://www.gottransition.org/youthfamilies/index.cfm
  - **Discovering**: learn about your provider's approach to transition
  - **Tracking**: know your own health information
  - **Preparing**: learn to manage your own health care
  - **Planning**: get ready for adult health care
  - **Transferring**: make the change to an adult provider
  - **Completing**: providing feedback

Discovering

- Ask current providers what age do they transition patients out of their practice
- Do they have recommendations for an adult provider?
- Does the office have different approaches between adult and adolescent patients if they are family practice?

Tracking, Preparing and Planning

- Where to start?
  - Transition readiness assessment (via Got Transition)
    - Assesses knowledge about own health and current ability to navigate healthcare system
    - Good initial assessment to jump start conversation and and identify areas to work on
    - Link to youth assessment: https://www.gottransition.org/resourceGet.cfm?id=224
    - Link to parent assessment: https://www.gottransition.org/resourceGet.cfm?id=225

- Practice health care skills
  - Talking to nursing staff, answering/ asking questions of the doctor, calling the pharmacy for medications, etc
  - Use readiness assessment as guide for what skills to work on

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Transition Readiness Assessment

My Health — *Please check the box that applies to you right now.*	*Yes, I know this*	*I need to learn*	*Someone needs to do this… Who?*
I know my medical needs.	☐	☐	☐
I can explain my medical needs to others.	☐	☐	☐
I know my symptoms including ones that I quickly need to see a doctor for.	☐	☐	☐
I know what to do in case I have a medical emergency.	☐	☐	☐
I know my own medicines, what they are for, and when I need to take them.	☐	☐	☐
I know my allergies to medicines and medicines I should not take.	☐	☐	☐
I carry important health information with me every day (e.g. insurance card, allergies, medications, emergency contact information, medical summary).	☐	☐	☐
I understand how health care privacy changes at age 18 when legally an adult.	☐	☐	☐
I can explain to others how my customs and beliefs affect my health care decisions and medical treatment.	☐	☐	☐
Using Health Care			
I know or I can find my doctor's phone number.	☐	☐	☐
I make my own doctor appointments.	☐	☐	☐
Before a visit, I think about questions to ask.	☐	☐	☐
I have a way to get to my doctor's office.	☐	☐	☐
I know to show up 15 minutes before the visit to check in.	☐	☐	☐
I know where to go to get medical care when the doctor's office is closed.	☐	☐	☐

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Planning: concise medical summary

- Goal is to have easy to read medical summary that can highlight important, need to know information for a new medical provider
- Can also use this as a guide for communicating important medical information (ie help adolescent communicate medical history to check-in staff at office or if in ED/ urgent care)
- There are different templates and no one perfect option

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CUMULATIVE PATIENT PROFILE

For adults with IDD

Adapted from template originally developed by the Department of Family and Community Medicine, Faculty of Medicine, University of Toronto, and Electronic Medical Record, DFCM, St. Michael's Hospital, Toronto

Initial Assessment Completed: ___/___/___ (dd mm yyyy)

Consider annual review, and update sooner when changes occur, e.g., decision-making capacity

Last/First Name: _____

Address: _____

_____

Etiology of DD: _____

☐ Definite ☐ Probable ☐ Possible ☐ Unknown

Phone: _____ DOB ___/___/___ (dd mm yyyy) Gender: ____

Medical Record Number: _____

Genetic assessment: ☐ No ☐ Yes **Date:** ___/___/___

Report on file? ☐ No ☐ Yes

Findings of genetic assessment:

Psychological assessment: ☐ No ☐ Yes **Date:** ___/___/___

Report on file? ☐ No ☐ Yes

Findings of psychological assessment:

Living situation:

☐ Lives alone ☐ Lives with family ☐ Group home

☐ Supported living ☐ Nursing Home ☐ Other

Level of adaptive functioning:

☐ Mild ☐ Moderate ☐ Severe

☐ Profound ☐ Unknown

Last grade/degree completed: _____

Approximate reading level: _____

DECISION-MAKING CAPACITY

Decision-Making Capacity:

☐ Capable ☐ Not capable ☐ Unsure

Substitute Decision Maker:

Name: _____

http://vkc.mc.vanderbilt.edu/etoolkit/wp-content/uploads/cumpatientprofile.pdf

My Health Passport

If you are a *health care professional* who will be helping me,
PLEASE READ THIS
before you try to help me with my care or treatment.

My full name is: _____

I like to be called: _____

Date of birth: ___/___/_____

My primary care physician: _____

Physician's phone number: _____

Attach your picture here!

This passport has important information so you can better support me when I visit/stay in your hospital or clinic.

Please keep this with my other notes, and where it may be easily referenced.

http://flfcic.fmhi.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_English.pdf

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got transition

Sample Medical Summary and Emergency Care Plan

Six Core Elements of Health Care Transition 2.0

This document should be shared with and carried by youth and families/caregivers.		
Date Completed:	Date Revised:	
Form completed by:		
Contact Information		
Name:	Nickname:	
DOB:	Preferred Language:	
Parent (Caregiver):	Relationship:	
Address:		
Cell #: Home #:	Best Time to Reach:	
E-Mail:	Best Way to Reach: Text Phone Email	
Health Insurance/Plan:	Group and ID #:	
Emergency Care Plan		
Emergency Contact:	Relationship:	Phone:
Preferred Emergency Care Location:		
Common Emergent Presenting Problems	Suggested Tests	Treatment Considerations

http://gottransition.org/resourceGet.cfm?id=227

MEDICAL SUMMARY AND EMERGENCY ACTION PLAN

LAST UPDATED:

PATIENT CONTACT INFORMATION	EMERGENCY CONTACT
Name: Goes by: Date of Birth: Address: Phone number: Email: Insurance:	Name: Goes by: Phone number: Relation to Patient: Preferred emergency care location:
MEDICAL DECISION-MAKING Can make own medical decisions? YES NO Substitute decision-maker? YES NO	**CONTACT INFORMATION OF DECISION-MAKER** Same as emergency contact? YES NO Title (guardian, power of attorney): Name: Goes by: Address: Phone number: Relation to Patient:
ALLERGIES (Include type of reaction)	
PRIMARY DIAGNOSES: (date of onset, etiology, current status)	

Dressler, Paul B, Moody, Eric J, Nguyen, Teresa K, Friedman, Sandra L, Pickler, Laura. "Use of Transition Resources by Primary Care Providers for Youth with Intellectual and Developmental Disabilities". To be published IDD

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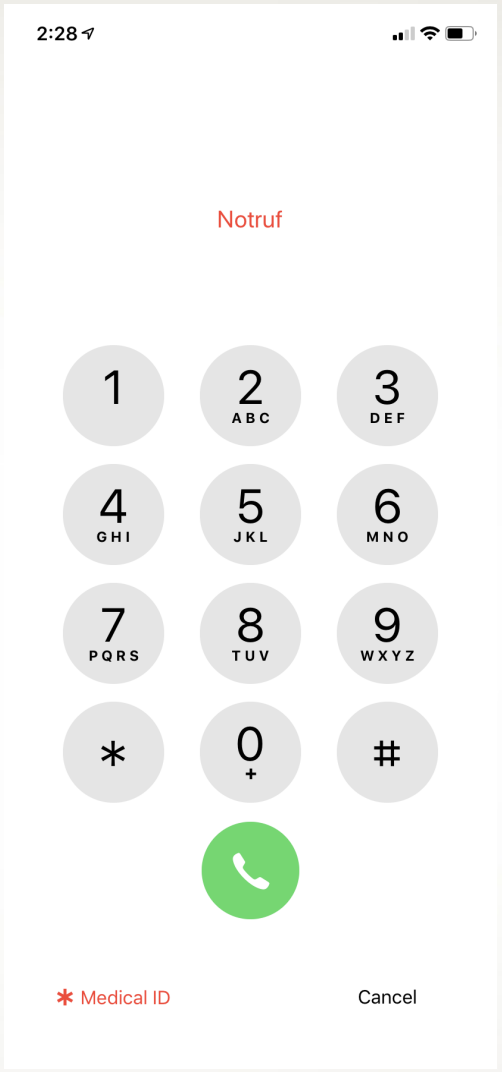

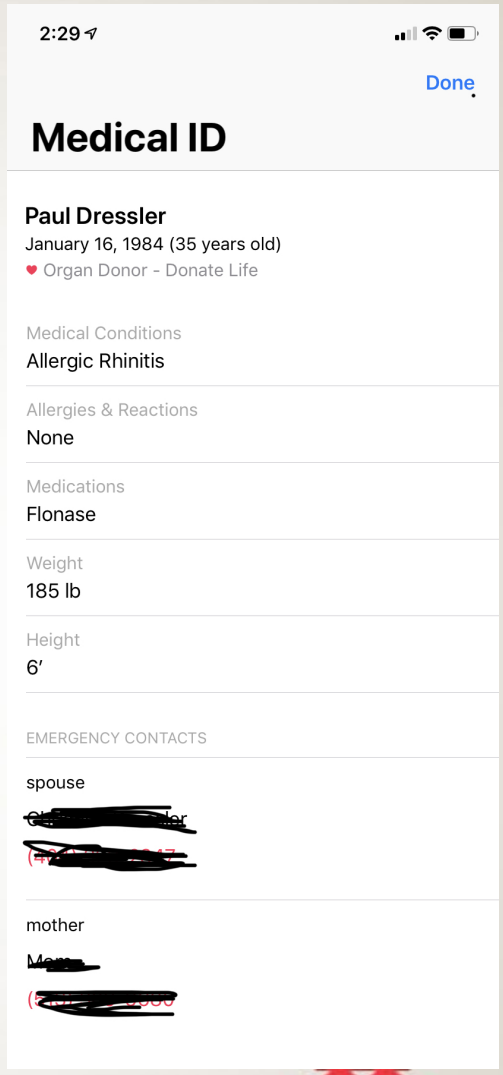

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Planning the Transfer

- Where to find adult provider
  - Does current primary care provider or other specialists have recommendation?
  - Do you/ your parents have a primary care provider?
    - If so, would they be a good fit?
  - What insurance will you have as an adult and when will that change occur?
    - Might consider transferring before losing parents' insurance as a practice is more likely to keep a patient they have developed a relationship with versus refusing at outset due to insurance issues. However, this is becoming harder to do
- What to look for in adult provider/ practice
  - Patient and flexible: both provider as well as front desk and nursing staff
  - Continuity of provider: same provider at each visit or different provider each time
  - Willing to learn about medical and behavioral needs (ie do not have to be an expert in diagnosis; just willing to learn)
  - Consider touring the practice and interviewing providers

Transfer

- Gather important medical documents and medical summary
- Communicate with both pediatric and adult offices to ensure medical records were transferred
- Have all (if any) shared decision making documents available

Shared/ Supported Decision-Making

- Differs between every state
- No one way to go about this
- Considerations:
  - Conservatorship/ guardianship is more challenging to obtain and more challenging to take away
  - Will your adult child eventually learn skills to further independence?
  - All young adults have a right to mess up and make poor decisions
- The following are definitions for the state of Tennessee but are similar to other states

Conservatorship

"Conservatorship is a legal process by which the court gives decision-making responsibilities to a conservator in areas in which the respondent (the legal term for the person who is the subject of the proceeding) does not have the capacity to make or understand the consequences of his or her decisions."

"An attorney must first prepare and file a Petition for Conservatorship with the appropriate court. A guardian ad litem, also an attorney, will then be appointed to report to the court as to the appropriateness of a conservatorship and the appropriateness of the proposed conservator. As part of the process a medical doctor or a licensed psychologist must examine the person and make a sworn statement regarding his or her functional abilities and need or lack of need for a conservator to assist with decision making in different areas. If the respondent wishes to contest the appointment of a conservator, an attorney ad litem, representing the respondent only, may be appointed. Those rights to be removed from the respondent and vested in a conservator, if any, will be determined by the court after a hearing."

From the Conservatorship Association of Tennessee website:
http://www.catenn.org/questions/faqs

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Alternatives to Conservatorship

- Durable Power of Attorney

"A durable power of attorney (DPOA) is a legal document that gives someone authority to make decisions on behalf of another individual. DPOA may be given for healthcare or financial decision-making. A DPOA for educational decision-making can be established once a student turns 18, if the student needs and wants assistance in making decisions about his/her Individualized Education Program (otherwise, the right to sign the IEP transfers to the student). The DPOA must be in writing and notarized. In order for the DPOA to be valid, the individual must be considered competent at the time s/he signs the document. People with significant intellectual disabilities may not understand the idea of a DPOA and so are unlikely to be considered competent. The attorney should document the involvement of the individual with a disability in the decision-making process. The person must be able to indicate clearly that s/he wants a certain individual to make decisions on her/his behalf."

- Representative Payee

"The administrator of these benefits, such as the Social Security Administration (SSA), may assign a representative payee. The payee receives the check and must use the money to benefit the individual. In some cases, family members serve as representative payees. Organizations (i.e., community mental health centers or Medicaid Waiver providers) also can serve as representative payees. The payee must account for the use of the benefit check, and is liable to repay money if it is mismanaged."

From the ARC of Tennessee Conservatorship Handbook:
https://www.thearctn.org/Assets/Docs/Conservatorship_Handbook.pdf

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Resources for shared/ supported decision making

- www.supporteddecisionmaking.org – National group that goes over various options
- Tennessee Council on Developmental Disabilities website have tool-kit and video going over supported decision making options
  - https://www.tn.gov/cdd/public-policy/supported-decision-making.html

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References

- Sullivan WF, Berg JM, Bradley E, Cheetham T, Denton R, Heng J, Hennen B, Joyce D, Kelly M, Korossy M, Lunsky Y, McMillan S. "Primary care of adults with developmental disabilities: Canadian consensus guidelines." Can Fam Physician. 2011 May;57(5):541-53, e154-68.
- Wee LE, Koh GCh, Auyong LS, Cheong AL, Myo TT, Lin J, Lim EM, Tan SX, Sundaramurthy S, Koh CW, Ramakrishnan P, Aariyapillai-Rajagopal R, Vaidynathan-Selvamuthu H, Khin MM. "The medical, functional and social challenges faced by older adults with intellectual disability." Ann Acad Med Singapore. 2013 Jul;42(7):338-49.
- Lewis MA, Lewis CE, Leake B, King BH, Lindemann R. "The quality of health care for adults with developmental disabilities." Public Health Rep. 2002 Mar-Apr;117(2):174-84.
- Virji-Babul N, Eichmann A, Kisly D, Down J, Haslam RH. "Use of health care guidelines in patients with Down syndrome by family physicians across Canada." Paediatr Child Health. 2007 Mar;12(3):179-83.
- Jensen KM, Davis MM. "Health care in adults with Down syndrome: a longitudinal cohort study." J Intellect Disabil Res. 2013 Oct;57(10):947-58. doi: 10.1111/j.1365-2788.2012.01589.x. Epub 2012 Jul 10.
- Pickler L., Kellar-Guenther Y., Goldson E. "Barriers to transition to adult care for youth with intellectual disabilities". J Child Adolesc Health 3. 575-584.2011
- Peter NJ, Forke CM, Ginsberg KR, Schwartz DF. "Transition From Pediatric to Adult Care: Internists' Perspectives". Pediatrics Vol. 123 No. 2 February 1, 2009 , pp. 417 -423 (doi: 10.1542/peds.2008-0740)
- Got Transition 6 Core Elements of Health Care Transition 2.0
- "Prepared by the Got Transition/Center for Health Care Transition Improvement project team, Margaret McManus, Patience White, and Megan Prior, with assistance from our cabinet executive team, Jeanne McAllister, Carl Cooley, Eileen Forlenza, Laura Pickler, Mallory Cyr, Nienke Dosa, Teresa Nguyen, Tawara Goode, and Wendy Jones, and our federal Maternal and Child Health Bureau project officer, Marie Mann."
- Dressler, Paul B, Moody, Eric J, Nguyen, Teresa K, Friedman, Sandra L, Pickler, Laura. "Use of Transition Resources by Primary Care Providers for Youth with Intellectual and Developmental Disabilities". To be published in IDD.

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