



Health Care Transition, Person Centered Thinking
&
Supporting Families of/and Individuals with
Intellectual & Developmental Disabilities

Presented by:
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The Institute for Person Centered Practices
A Collaborative Partnership with The Center on Disability Studies at the University of Texas and
The Center on Disability and Development at Texas A&M University



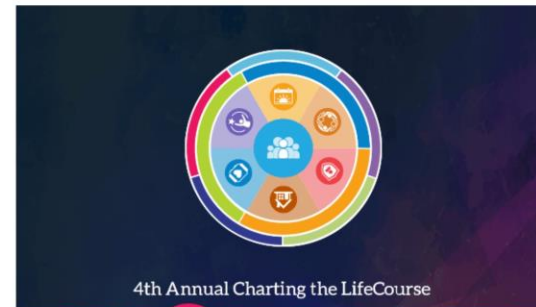
Welcome to our **Community** of Learning

Charting the LifeCourse is designed to be used for your own life, for your family members, or in the work you do. The framework and tools will help you organize your ideas, vision, and goals, as well as problem-solve, navigate, and advocate for supports.



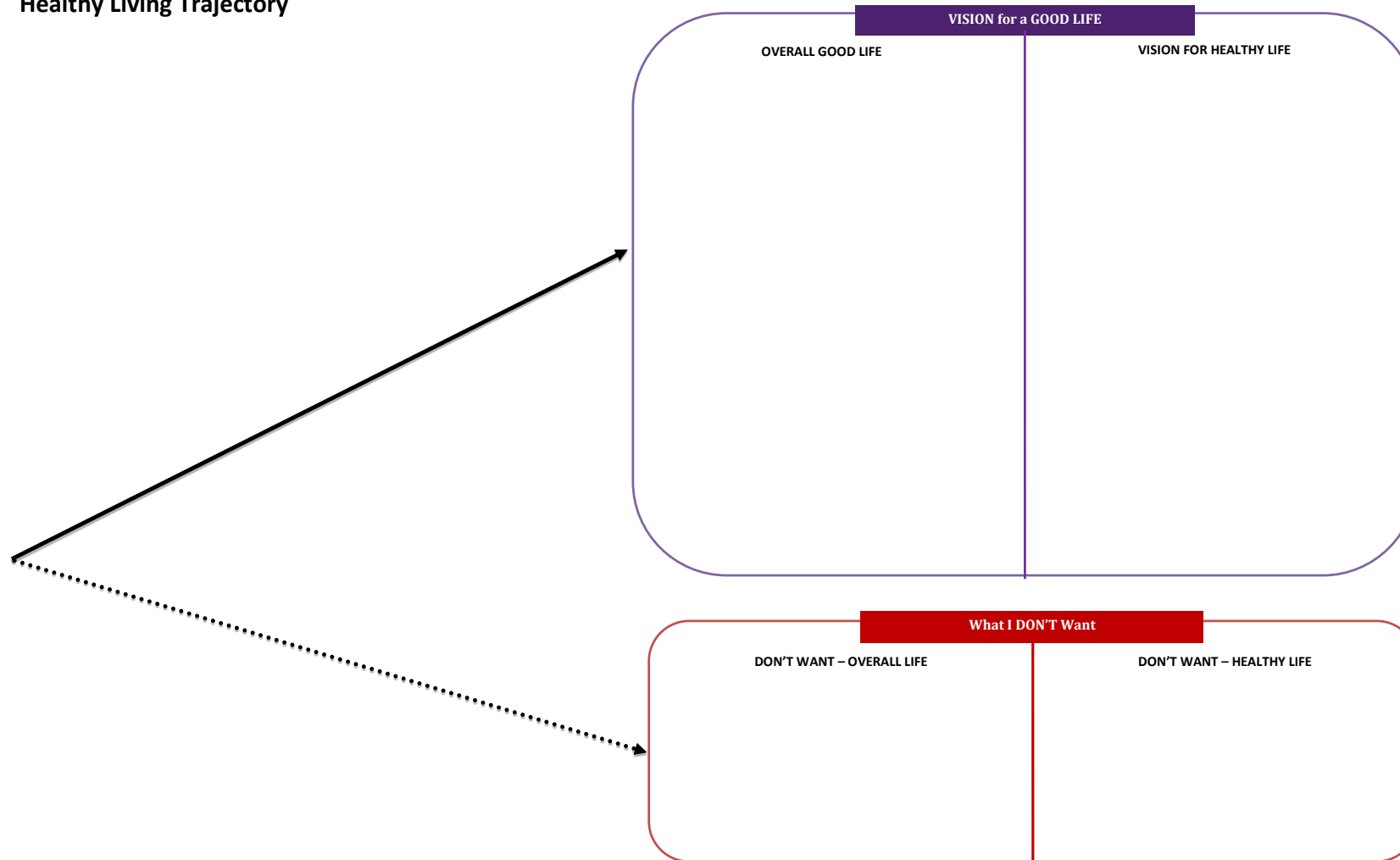
What can Charting the LifeCourse do for **You**?

- People are using it to communicate their needs.
- People are advocating for the supports they need to accomplish their goals.
- Parents are setting higher expectations for their children.
- Students are learning how life experiences impact their career goals.
- Families are exploring the resources and supports they need.



4th Annual Charting the LifeCourse

Healthy Living Trajectory



Developed by the UMKC Institute for Human Development, UCEDD | More tools and resources at [lifecoursetools.com](https://www.lifecoursetools.com/)

Updated NOV 2016

A Core Concept and a Core Skill Balancing Important **to** and Important **for**

Important TO	Important FOR
<p>What is important to a person includes those things in life which help us to be satisfied, content, comforted and happy. It includes:</p> <ul style="list-style-type: none">• People to be with/ relationships• Things to do• Places to go• Rituals or routines• Rhythm or pace of life• Status & control• Things to have <p>It includes what matters most to the person – their own definition of quality of life.</p> <p>What is important to a person includes only what the person “says”:</p> <ul style="list-style-type: none">• with their words• with their actions <p>When words and actions are in conflict, listen to action. Ask why?</p>	<p>What is important for a person includes:</p> <p>Issues of health:</p> <ul style="list-style-type: none">• Prevention of illness• Treatment of illness / medical conditions• Promotion of wellness (e.g.: diet, exercise) <p>Issues of safety:</p> <ul style="list-style-type: none">• Environment• Well being - physical and emotional• Free from Fear <p>What others see as necessary to help the person:</p> <ul style="list-style-type: none">• Be valued• Be a contributing member of their community

YOUTH & YOUNG ADULTS

Transitioning to adult health care is a big step in your life. Got Transition has tools and resources for you to help make it a smooth process!

[LEARN MORE](#)

Got Transition aims to help youth and young adults move from pediatric to adult health care.

[Six Core Elements™
\(For Clinicians\)](#)
[Youth & Young Adults
\(FAQs & Resources\)](#)
[Parents & Caregivers
\(FAQs & Resources\)](#)
[Resources & Research
\(By Category\)](#)

News & Announcements

Updated Six Core Elements of Health Care Transition™ 3.0 out now!

Got Transition has updated its Six Core Elements of Health Care Transition™ with revised tools, samples, and recommendations.

Step-by-Step Implementation Guides for the Six Core Elements

Got Transition now offers step-by-step Implementation Guides for each Six Core Element with real world examples for practices.

Family Toolkit on Health Care Transition

A toolkit from Got Transition developed for families to use during the transition from pediatric to adult health

care.

Are you ready to take charge of your health? These 5 easy steps should help you find out!

2020 Transition Coding and Reimbursement Tip Sheet Available

Got Transition and the American Academy of Pediatrics have released their 2020 Transition Coding and Reimbursement Tip Sheet, which includes new CPT codes, current Medicare fees and RVUs for the codes, and more.

2020 Transition Conferences

Save the Date for two health care transition conferences (October 28-30, 2020)

For more News and Announcements, click here.



Youth & Young Adults: Are You Ready to Transition to Adult Care?

[TAKE THE QUIZ](#)


Parents & Caregivers: Is Your Child Ready to Transition to

Side-by-Side Comparison

The Six Core Elements of Health Care Transition™ 3.0 are intended for use by pediatric, family medicine, med-peds, and internal medicine practices to assist youth and young adults as they transition to adult-centered care. They are aligned with the AAP/AAFP/ACP Clinical Report on Health Care Transition.¹ Sample tools, implementation guidance, measurement, and payment resources are available at www.GotTransition.org.

TRANSITIONING YOUTH TO AN ADULT HEALTH CARE CLINICIAN <i>(For use by Pediatric, Family Medicine, and Med-Peds Clinicians)</i>	TRANSITIONING TO AN ADULT APPROACH TO HEALTH CARE WITHOUT CHANGING CLINICIANS <i>(For use by Family Medicine and Med-Peds Clinicians)</i>	INTEGRATING YOUNG ADULTS INTO ADULT HEALTH CARE <i>(For use by Internal Medicine, Family Medicine, and Med-Peds Clinicians)</i>
1. Transition and Care Policy/Guide <ul style="list-style-type: none"> • Develop a transition and care policy/guide with input from youth and parents/caregivers that describes the practice's approach to transition, an adult approach to care in terms of privacy and consent, and age of transfer to an adult clinician. • Educate all staff about the practice's approach to transition and distinct roles of the youth, parent/caregiver, and pediatric and adult health care team in the transition process, taking into account cultural preferences. • Display transition and care policy/guide somewhere accessible in practice space, discuss and share with youth and parent/caregiver, beginning at age 12 to 14, and regularly review as part of ongoing care. 	1. Transition and Care Policy/Guide <ul style="list-style-type: none"> • Develop a transition and care policy/guide with input from youth/young adults and parents/caregivers that describes the practice's approach to transition and an adult approach to care in terms of privacy and consent. • Educate all staff about the practice's approach to transition and distinct roles of the youth/young adult, parent/caregiver, and health care team in the transition process, taking into account cultural preferences. • Display transition and care policy/guide somewhere accessible in practice space, discuss and share with youth/young adult and parent/caregiver, beginning at age 12 to 14, and regularly review as part of ongoing care. 	1. Transition and Care Policy/Guide <ul style="list-style-type: none"> • Develop a transition and care policy/guide with input from young adults that describes the practice's approach to transition, accepting and partnering with new young adult patients, and an adult approach to care in terms of privacy and consent. • Educate all staff about the practice's approach to transition and distinct roles of the young adult, parent/caregiver, and adult health care team in the transition process, taking into account cultural preferences. • Display transition and care policy/guide somewhere accessible in practice space, discuss and share with young adult at first visit, and regularly review as part of ongoing care.
2. Tracking and Monitoring <ul style="list-style-type: none"> • Establish criteria and process for identifying transition-aged youth. • Develop process to track receipt of the Six Core Elements, integrating with electronic medical records (EMR) when possible. 	2. Tracking and Monitoring <ul style="list-style-type: none"> • Establish criteria and process for identifying transition-aged youth/young adults. • Develop process to track receipt of the Six Core Elements, integrating with electronic medical records (EMR) when possible. 	2. Tracking and Monitoring <ul style="list-style-type: none"> • Establish criteria and process for identifying transitioning young adults. • Develop process to track receipt of the Six Core Elements, integrating with electronic medical records (EMR) when possible.
3. Transition Readiness <ul style="list-style-type: none"> • Conduct regular transition readiness assessments, beginning at age 14 to 16, to identify and discuss with youth and parent/caregiver their needs for self-care and how to use health care services. 	3. Transition Readiness <ul style="list-style-type: none"> • Conduct regular transition readiness assessments, beginning at age 14 to 16, to identify and discuss with youth and parent/caregiver their needs for self-care and how to use health care services. 	3. Orientation to Adult Practice <ul style="list-style-type: none"> • Identify and list adult clinicians within your practice interested in caring for young adults. • Establish a process to welcome and orient new young adults


Side-by-Side Comparison (Continued)

TRANSITIONING YOUTH TO AN ADULT HEALTH CARE CLINICIAN <i>(For use by Pediatric, Family Medicine, and Med-Peds Clinicians)</i>	TRANSITIONING TO AN ADULT APPROACH TO HEALTH CARE WITHOUT CHANGING CLINICIANS <i>(For use by Family Medicine and Med-Peds Clinicians)</i>	INTEGRATING YOUNG ADULTS INTO ADULT HEALTH CARE <i>(For use by Internal Medicine, Family Medicine, and Med-Peds Clinicians)</i>
4. Transition Planning <ul style="list-style-type: none"> • Develop and regularly update the plan of care, including readiness assessment findings, youth's goals and prioritized actions, medical summary and emergency care plan, and, if needed, a condition fact sheet and legal documents. • Prepare youth and parent/caregiver for an adult approach to care, including legal changes in decision-making and privacy and consent, self-advocacy, and access to information. • Determine need for decision-making supports for youth and make referrals to legal resources. • Plan with youth and parent/caregiver for optimal timing of transfer from pediatric to adult care. If both primary and subspecialty care are involved, discuss optimal timing for each. • Assist youth in identifying an adult clinician(s) and provide linkages to insurance resources, self-care management information, and community support services. • Obtain consent from youth/parent/caregiver for release of medical information. • Take cultural preferences into account throughout transition planning. 	4. Transition Planning <ul style="list-style-type: none"> • Develop and regularly update the plan of care, including readiness assessment findings, youth/young adults' goals and prioritized actions, medical summary and emergency care plan, and, if needed, legal documents. • Prepare youth/young adult and parent/caregiver for an adult approach to care, including legal changes in decision-making and privacy and consent, self-advocacy, and access to information. • Determine need for decision-making supports for youth/young adult and make referrals to legal resources. • Plan with youth/young adult and parent/caregiver for optimal timing of transfer from pediatric to adult specialty care, if needed. • Provide linkages to insurance resources, self-care management information, and community support services. • Obtain consent from youth/young adult/parent/caregiver for release of medical information. • Take cultural preferences into account throughout transition planning. 	4. Integration into Adult Practice <ul style="list-style-type: none"> • Communicate with young adult's pediatric clinician(s) and arrange for consultation assistance, if needed. • Prior to first visit, ensure receipt of transfer package, including final transition readiness assessment, plan of care with transition goals and prioritized actions, medical summary and emergency care plan, and, if needed, legal documents, condition fact sheet, and additional clinical records. • Make pre-visit appointment reminder welcoming new young adult and identifying any special needs and preferences.
5. Transfer of Care <ul style="list-style-type: none"> • Complete transfer package, including final transition readiness assessment, plan of care with transition goals and prioritized actions, medical summary and emergency care plan, and, if needed, legal documents, condition fact sheet, and additional clinical records. • Confirm date of first adult clinician appointment. • Prepare letter with transfer package, send to adult clinician, and confirm adult clinician's receipt of transfer package. • Communicate with selected adult clinician about pending transfer of care. • Confirm the pediatric clinician's responsibility for care until youth/young adult is seen by an adult clinician. • Transfer youth/young adult when their condition is as stable as possible. 	5. Transition to Adult Approach to Care <ul style="list-style-type: none"> • Address any concerns youth/young adult has about transferring to an adult approach to care. • Clarify an adult approach to care (shared decision-making, privacy and consent, access to information), adherence to care, preferred methods of communication, and health literacy needs. • Conduct self-care skills assessment if not recently completed and discuss young adult's needs for self-care and how to use health care services. • Offer education and resources on needed skills identified through the self-care skills assessment. • Review youth/young adult's health priorities as part of their plan of care. • Continue to update and share with youth/young adult their medical summary and emergency care plan. 	5. Initial Visits <ul style="list-style-type: none"> • Prepare for initial visit by reviewing transfer package with appropriate team members. • Address any concerns young adult has about transferring to adult care and take into account any cultural preferences. • Clarify an adult approach to care (shared decision-making, privacy and consent, access to information), adherence to care, preferred methods of communication, and health literacy needs. • Conduct self-care skills assessment if not recently completed and discuss their needs for self-care and how to use health care services. • Offer education and resources on needed skills identified through the self-care skills assessment. • Review young adult's health priorities as part of their plan of care. • Update and share with young adult their medical summary and emergency care plan.
6. Transfer Completion <ul style="list-style-type: none"> • Contact youth/young adult and parent/caregiver 3 to 6 months 	6. Ongoing Care <ul style="list-style-type: none"> • Assist youth/young adult in connecting with specialists and other 	6. Ongoing Care <ul style="list-style-type: none"> • Communicate with pediatric practice confirming completion of transfer

<https://www.texaschildrens.org/health-professionals/conferences/21st-annual-chronic-illness-and-disability-conference-transition-pediatric-adult-based-care>

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Conferences

Health Professionals > Conferences > 21st Annual Chronic Illness and Disability Conference: Transition from Pediatric to Adult-Based Care

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21st Annual Chronic Illness and Disability Conference: Transition from Pediatric to Adult-Based Care

October 29-30, 2020

8:00 AM - 4:00 PM

Location

Jan and Duncan Neurological Research Institute
1250 Moursund St.
Houston, TX 77030

REGISTRATION COMING SOON

RESEARCH SYMPOSIUM 10/28 REGISTRATION COMING SOON

About this Event

Skill preparation and planning for healthcare transition for children and youth with special healthcare needs is inadequate. Less than 50 percent of families nationwide indicate that their children with special healthcare needs have received the services necessary to make appropriate transitions to adult healthcare, work, and independence. One of the major hurdles to receiving this care is the lack of a workforce, including physicians, nurses, social workers, mental health providers and all who provide services to youth and young adults with special healthcare needs trained to provide the services necessary to make the healthcare transition. There is a strong need for physicians to have the knowledge and skills to provide the services needed to facilitate a successful transition from pediatric to adult-based care and services.

Because of increased awareness of transitioning to adult-based care, clinicians are required to update their knowledge of the changing strategies for integrating emerging adult-based care into practice.

For all conference participants, there will be a discussion of the legal issues involved in healthcare transition, as well as time to meet and talk with faculty in small groups, to exchange ideas among participants, and to share knowledge and information about how best to plan for a successful transition to adulthood.

Costs

- Physician: \$350
- Nurse: \$225
- Social Worker: \$225
- Other Healthcare Professional: \$225
- BCM Faculty Member: \$175
- Medical Student: \$50
- Fellow: \$50
- Resident: \$50
- Youth: \$125
- Family Member: \$125

National Resource Center for Supported Decision-Making

EVERYONE has the Right To Make Choices

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Education

WELCOME TO THE NATIONAL RESOURCE CENTER FOR SUPPORTED DECISION-MAKING

Here, you'll find information about the **Right to Make Choices** – the right we **all** have to make our own decisions and direct our own lives. [Continue Reading >>](#)

Supported Decision-Making News

Highlights



<http://www.supporteddecisionmaking.org/>

's One Page Description

For Medical appointments

What People Like and Admire about ____

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Here

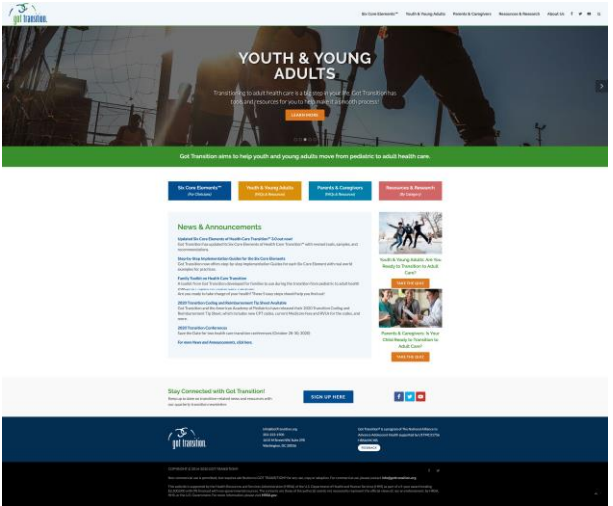
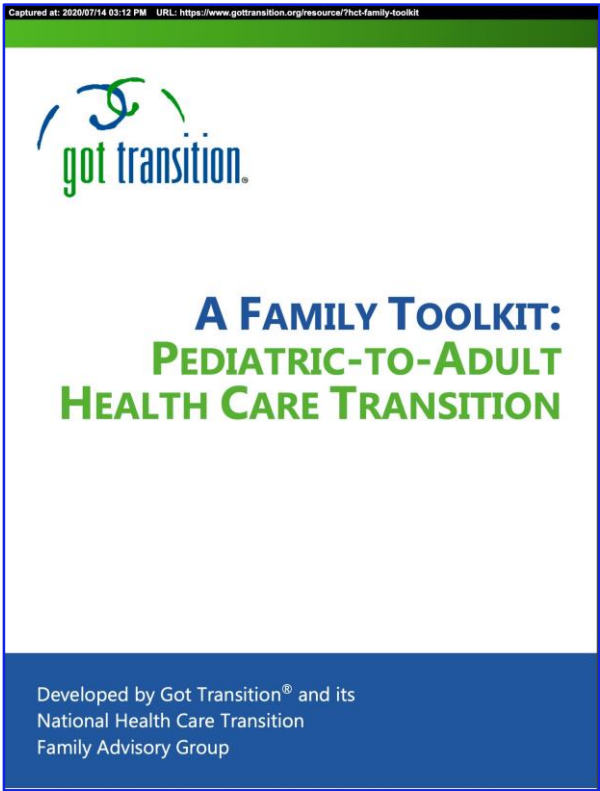
What is Important to

How to best support _____

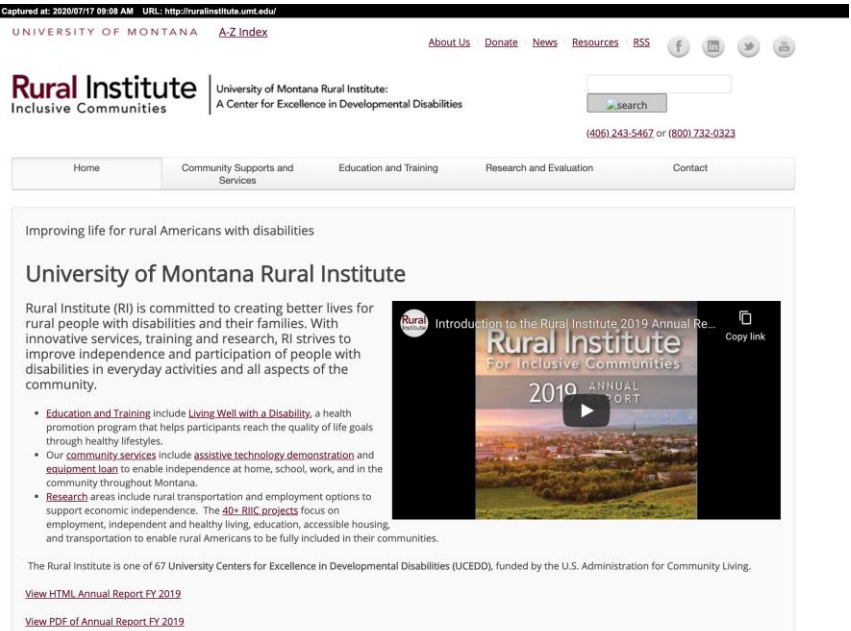
HEALTH CARE TRANSITION RESOURCES:



<http://www.supporteddecisionmaking.org/>

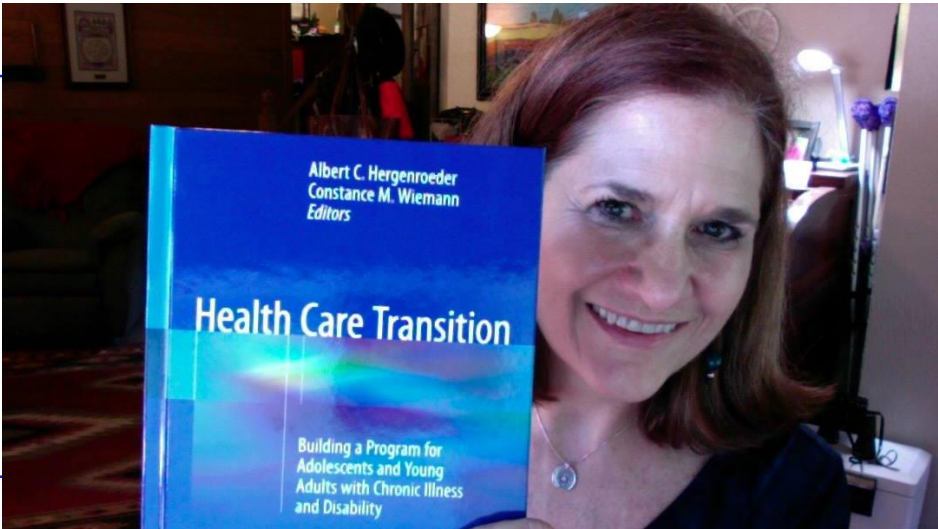


<https://www.gottransition.org/>



Health Care Transition: Building a Program for Adolescents and Young Adults with Chronic Illness and Disability

Albert C. Hergenroeder & Constance Wiemann, Editors





The University of Texas at Austin

Texas Center for Disability Studies

With thanks to
*The Learning Community for
Person Centered Practices*
(www.learningcommunity.us)

and

*The Community of Practice for
Supporting Families of Individuals
with Intellectual &
Developmental Disabilities*
<http://supportstofamilies.org/>

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<https://tcds.edb.utexas.edu/>