Pediatric to Adult Transition:

How to Get Started

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- I do not intend to discuss an unapproved/investigative use of a commercial product/device in my presentation.

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Objectives

- Identify available resources for creating a transition program
- Review the Pediatric to Adult Transition (PACT) Starter Kit
- Create an outline for your own clinic transition process

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Background

- Adolescents and emerging adults
- Period between ages 12-24

- Pediatric model → adult model of care
  - changes in privacy, decision making rights
  - expectations surrounding clinic support services and patient self-care abilities

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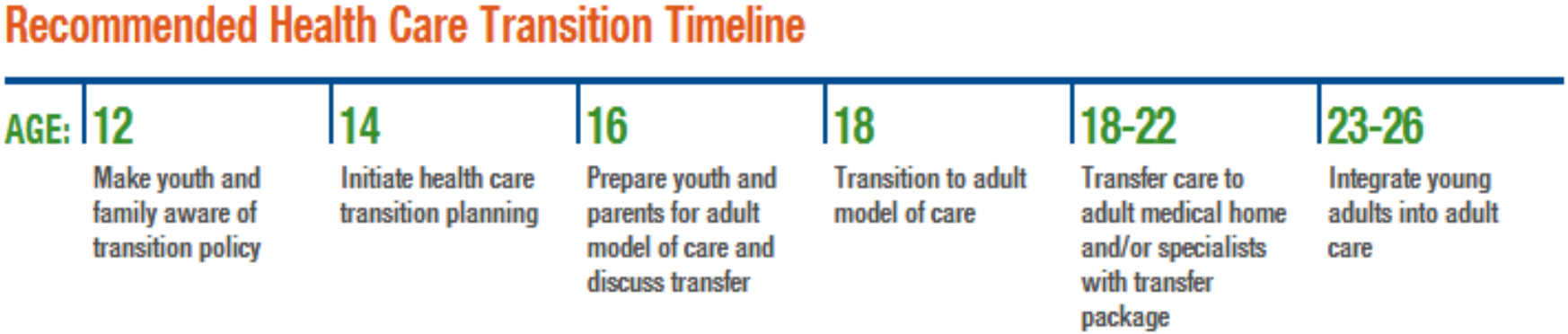
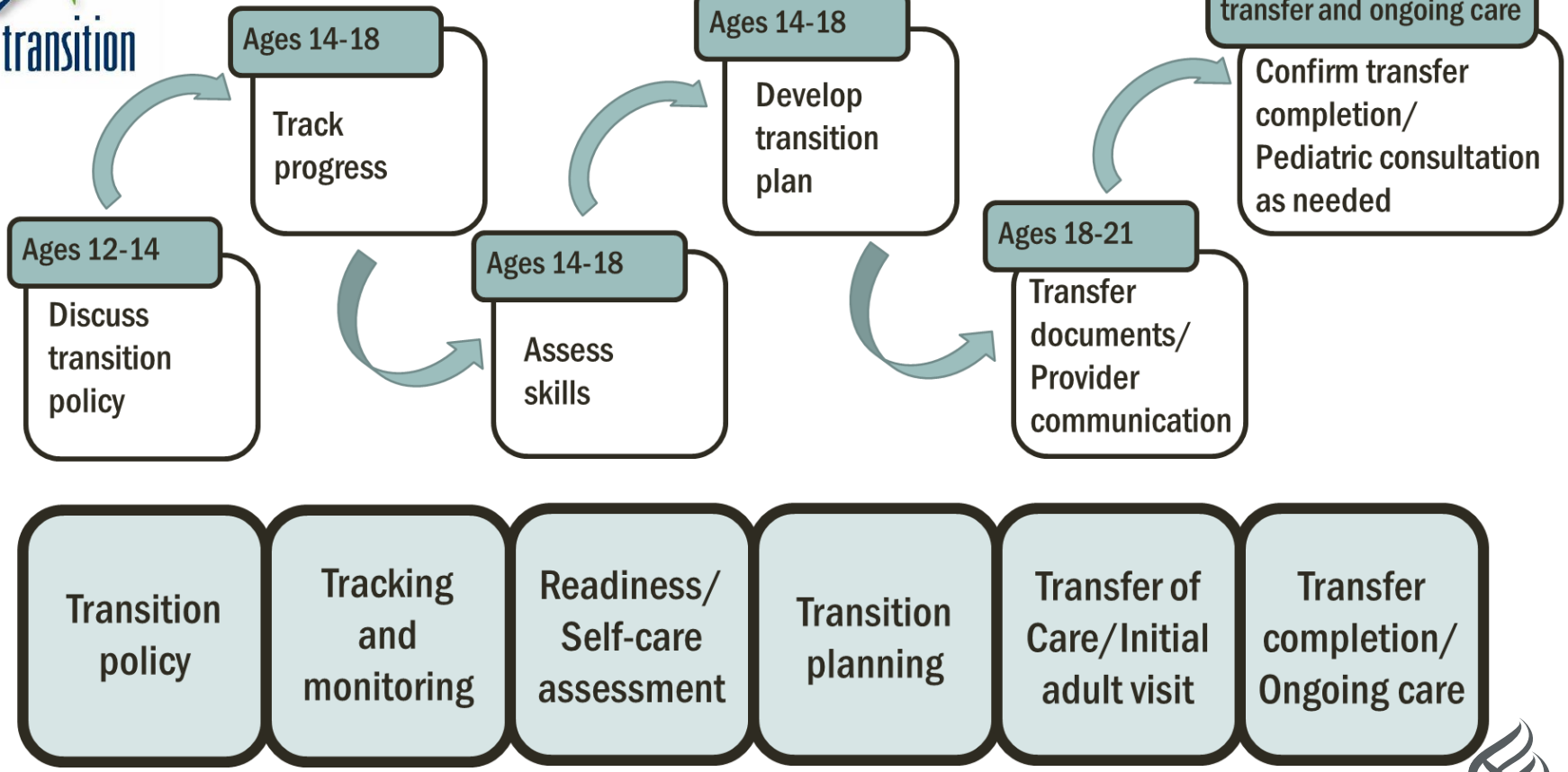
When?



"Six Core Elements of Transition"

www.gottransition.org/providers



www.gottransition.org
Arthritis & Rheumatology
Volume 68, Issue 4, pages 789-794, 28 MAR 2016 DOI: 10.1002/art.39554
http://onlinelibrary.wiley.com/doi/10.1002/art.39554/full#art39554-fig-0001

got transition

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About | News | Resources | Health Care Providers | Youth & Families | Researchers & Policymakers | Webinars

Got Transition aims to improve transition from pediatric to adult health care through the use of new and innovative strategies for health professionals and youth and families.

News & Announcements

Are you ready to transition to adult health care?

Take Our Quiz!

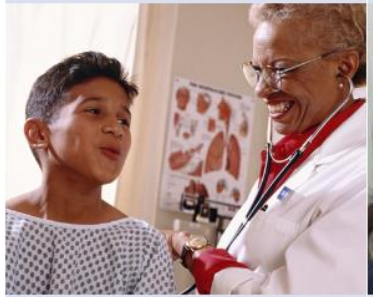
New Got Transition Webinar Series
Registration is open for Got Transition's new webinar series, "Health Care Transition & Title V Care Coordination Initiatives." more>

AAP Transition ECHO
The American Academy of Pediatrics Transition ECHO offers a standardized curriculum on health care transition more>

New Transition of Care Video Series for Neurology

Health Care Providers

Find out about how to implement health care transition quality improvement in your practice or plan using the new Six Core Elements of Health Care Transition (2.0). Download accompanying clinical resources and measurement tools for use in any setting.

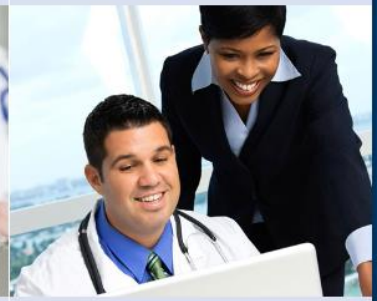


Youth & Families

Hear what young adult and parent experts have to say about common transition questions and discover new resources to make this process work easier.

Researchers & Policymakers

Find new transition policy developments, research and measurement approaches, and federal and state transition initiatives.



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AAP Transition ECHO

Support transition from pediatric to adult care

OVERVIEW

The AAP Transition ECHO serves as a forum for health care professionals to learn how to successfully transition youth from pediatrics to the adult care system. This virtual community builds a bi-directional knowledge network whereby participants learn from experts and each other, gaining access to evidence-based and capacity-building resources. Each clinic includes a brief presentation by a national transition expert, followed by in-depth, practice-based presentations for discussion, problem-solving guidance and recommendations. All attendees are invited to share and actively participate. Through regular attendance, participants will use quality improvement techniques to support planning and transfer of care to ensure that all youth and young adults, including those with epilepsy, successfully transition into adult care.

All healthcare professionals, including office staff, who have an interest in improving transitional care for youth and young adults (including patients with epilepsy) are welcome to participate. Participants will receive the following benefits from participating in the ECHO clinic:

- Receive up-to-date information on clinical recommendations from the Clinical Report on Transition and nationally recognized transition model, "Six Core Elements of Health Care Transition".
- Acquire evidence-based health care transition tools and resources.
- Identify quality improvement lessons learned around transition from colleagues caring for youth and young adults with epilepsy.
- Access guidance and recommendations related to transition from peers and national experts.

CURRICULUM

ACP Pediatric to Adult Care Transitions Initiative

About This Project

Condition-Specific Tools

General Internal Medicine

- Intellectual/Developmental Disabilities
- Physical Disabilities

Cardiology

Endocrinology

Gastroenterology

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Oregon Family to Family Health Information Center

Resources For Health Care Transition

http://oregonfamilytofamily.org

Overview of adolescent transition to adult health care

As children get closer to adulthood, they have different needs. By the time they are 18 they need a solid transition plan, even if they still need support. Find resources for patients aged 12-25.

Got Transition.org

Teen's Rights to Access, Confidentiality, and HIPAA

Maternal Child Health Information on Care for Adolescents and Young Adults

American College of Physicians: Condition-specific transition materials

Tools to use with transition-age youth and families

Support your patients and their families with these helpful resources.

Transition Planning Checklist

Preparing Families for Transition

OR Dept. of Education Transition Planning

National Gateway to Self-Determination

Transition Readiness Assessment (Health)

Adolescent Autonomy Checklist (SPAN NJ)

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Pediatric to Adult Care Starter Kit

- Where do I start?
- Practical next steps
- Modeled on experience at OHSU:
  - General Pediatrics
  - General Internal Medicine
  - Work with Subspecialty clinics

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1. Build Your Team

- Champions are needed
- Involve all team members
  - interprofessional effort

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2. Set goals and timelines

- Many points of intervention
  - consider when to initiate and follow up with patients
- Will depend on clinic bandwidth and priorities
- Communication is key

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3. Decide….

- Which patients to target
- How to introduce program to patients
- Which health management self-assessment tools
- Who will complete a ‘health passport’

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Which patients?

- Healthy, typically developing adolescent
- Adolescent with chronic health condition but no impact on cognition
- Adolescent with significant intellectual disability precluding ability to care for self or make independent decisions

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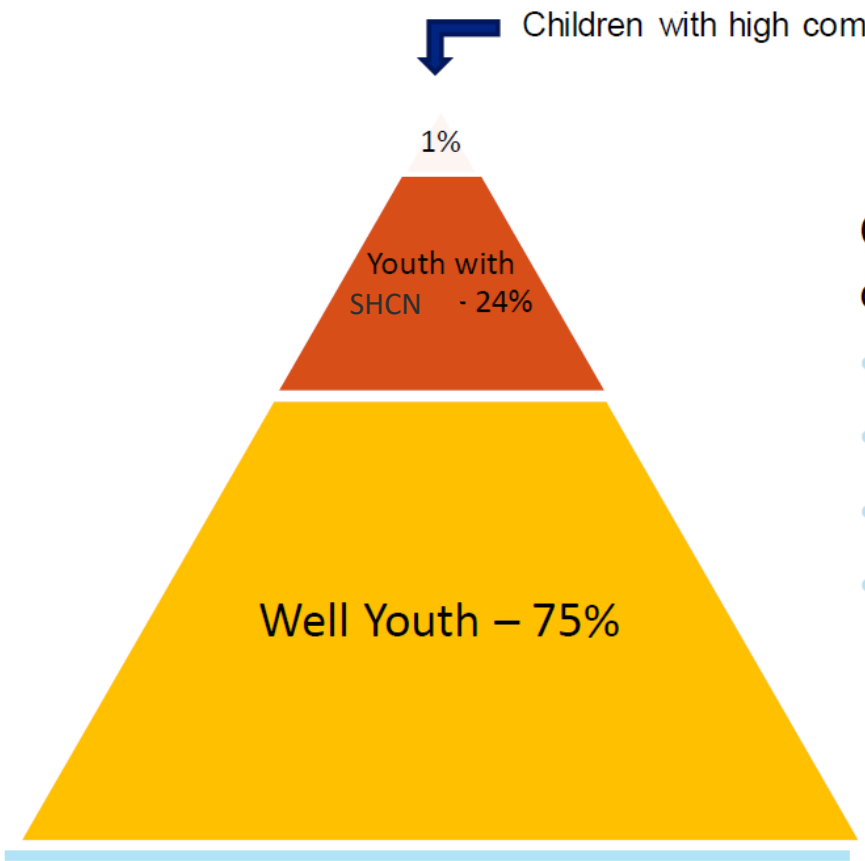
Children with & without Special Health Care Needs



Categories of chronic conditions

- Chronic illness
- Physical disability
- Intellectual disability
- Serious mental illness

How to introduce

- Letters, handouts, phone outreach
- Face to face visits

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Transition Beyond Health Care

Health care is important, but it's not your whole life. Here are some things to consider as you prepare to transition into your life as an adult.

- Stay connected with others. Friends are important for your mental health.
- Participate in hobbies and social activities that you enjoy.
- Start doing things for yourself around the house (laundry, dishes, etc.).
- Attend your IEP meetings at school. Discuss your goals and needs.
- In public, make sure you are aware of your surroundings. Let someone know about your plans if you are doing something unfamiliar.
- Learn about money: earning, saving, and spending. Practice making purchases.
- What are your neighborhood's transportation options? Know how to use the bus.
- Explore what living away from home would look like by talking to your family and friends who live independently.
- Start planning what you will do after high school. Apply for college, a job, or housing.

For Parent/Guardian:

- Encourage your teen's independence. Facilitate social activities they can do on their own.
- Support independence at home (laundry, pet-care, self-care, increased responsibility, etc.).
- Introduce paying bills and financial planning.
- Talk with your teen about career interests and educational goals.
- Inquire about your teens school transition services. Include transition planning in the IEP by age 16.
- Consider opportunities for your teen to find work and participate in volunteer activities.
- Assist your teen with applications for college, employment or housing.

Institute on Development & Disability
www.ohsu.edu/idd
transition@ohsu.edu

Revised: June 2016

Transitioning to Adult Health Care

Guide for Teens and Families

OHSU Institute on Development and Disability
Child Development and Rehabilitation Center
OHSU

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Birthday letter, age 13

Dear *** and family,

Happy 13th birthday! You are becoming a teen. We are here to support you and help you learn how to stay healthy.

We like to spend a little time with you during your visits without adults in the room. This allows you to ask questions, set health goals, and learn to be more independent.

A few suggestions for you:

- Learn about your medical conditions
- Learn what medications you are taking (if any). Make sure you don't run out
- Know who to call for help in an emergency or if you feel unsafe
- Talk to an adult you trust when you have questions about your body, your mood, and other things that affect your health

A few suggestions for your parent or guardian:

- Review the enclosed information for teens and families
- Help your teen learn about how to talk about medical conditions they have
- Help them practice asking their health care providers questions at appointments
- Give your teen responsibilities and teach skills that will allow them to take charge of his or her health as they grow

Self-assessment tool

- Many resources available
- Create one that works for you
- Consider medical, social, educational, vocational needs

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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 the medicines I should not take.		☐	☐	☐
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.		☐	☐	☐
I have a file at home for my medical information.		☐	☐	☐
I know how to fill out medical forms.		☐	☐	☐
I know how to get referrals to other providers.		☐	☐	☐
I know where my pharmacy is and how to refill my medicines.		☐	☐	☐
I know where to get blood work or x-rays done if my doctor orders them.		☐	☐	☐
I carry important health information with me every day (e.g. insurance card, allergies, medications, emergency contact information, medical summary).		☐	☐	☐

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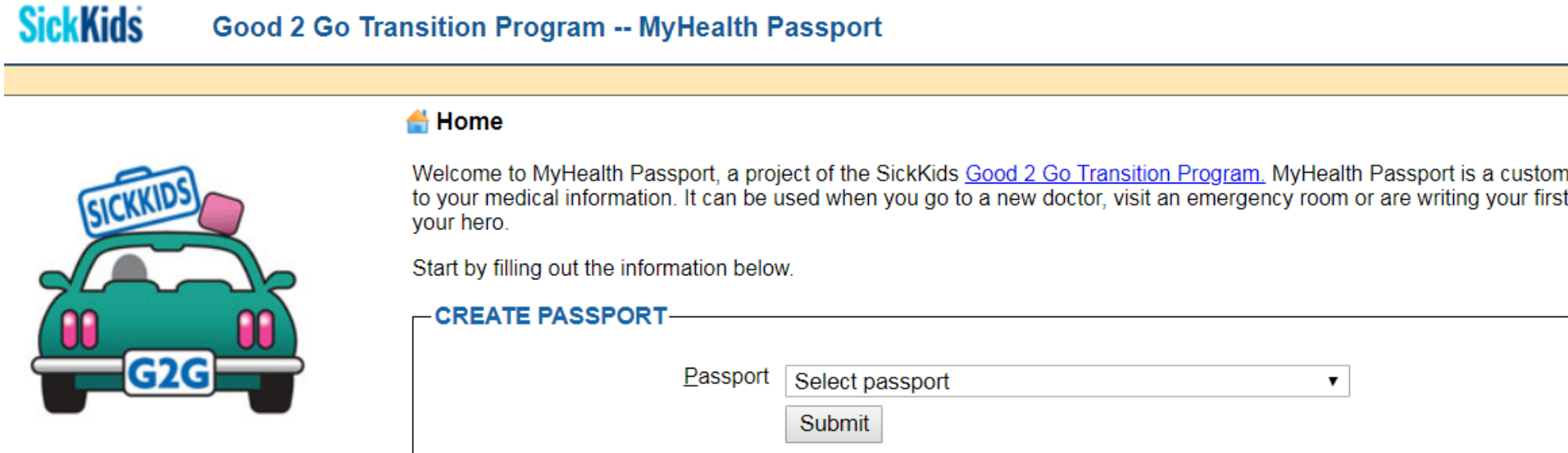
Health passport

- Use as a teaching and organizational tool
- Resources available or create your own



MY MEDICAL TEAM (include MD, PA, NP, PT, OT, speech, psychology, etc):

Name	Specialty	Phone number	What problem does this provider manage

MY MEDICAL PROBLEMS

Surgeries (include date)

Other important health history

Allergies: _____

Special Needs: _____

DAILY MEDICATION

Name	Dose	How many times a day	Why

4. Collect resources

- Resources available or create your own
  - Partner with local community organizations
- Have a follow up plan for resource gaps

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RESOURCES FOR TRANSITION

Basic Process

Got transition? www.gottransition.org

ACP: https://www.acponline.org/clinical-information/high-value-care/resources-for-clinicians/pediatric-to-adult-care-transitions-initiative/condition-specific-tools

AAP: https://www.aap.org/en-us/professional-resources/practice-transformation/echo/Pages/Transition.aspx

QI/MOC credit: http://illinoisaap.org/projects/medical-home/transition/

Coding/Reimbursement Tip Sheet: https://www.gottransition.org/resourceGet.cfm?id=352

2018 *Pediatrics* update "Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home" http://pediatrics.aappublications.org/content/142/5/e20182587

Supporting Self-Management Skills

Assessments

- Am I On TRAC? For Adult Care Questionnaire

http://www.bcchildrens.ca/health-professionals/clinical-resources/transition-to-adult-care

- Boston Children's Hospital ADAPT Survey

http://www.childrenshospital.org/Research/Centers-Departmental-Programs/center-of-excellence-for-pediatric-quality-measurement-cepqm/cepqm-measures/transition-from-child-focused-to-adult-focused-care

- Readiness for Transition Questionnaire (RTQ) (Kidney transplant)
- Transition Readiness Assessment Questionnaire (TRAQ) https://www.etsu.edu/com/pediatrics/traq/
- UNC STARx questionnaire (available in English, Spanish, Danish)

https://www.med.unc.edu/transition/transition-tools/trxansition-scale/versions-of-the-starx-questionnaire/

5. Pilot with 2-5 patients

- Assess medical, social, educational, vocational, community, transition resource needs

- Consider a QI framework for collecting baseline data and cycles of improvement

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6. Identify gaps, set goals, create an action plan

- Engage the patient!
- Decide who will be leading interactions
- Assess needs with each patient
- Document - consider how to integrate into EHR

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7. Track and measure

- Create a database
- Integrate into EHR

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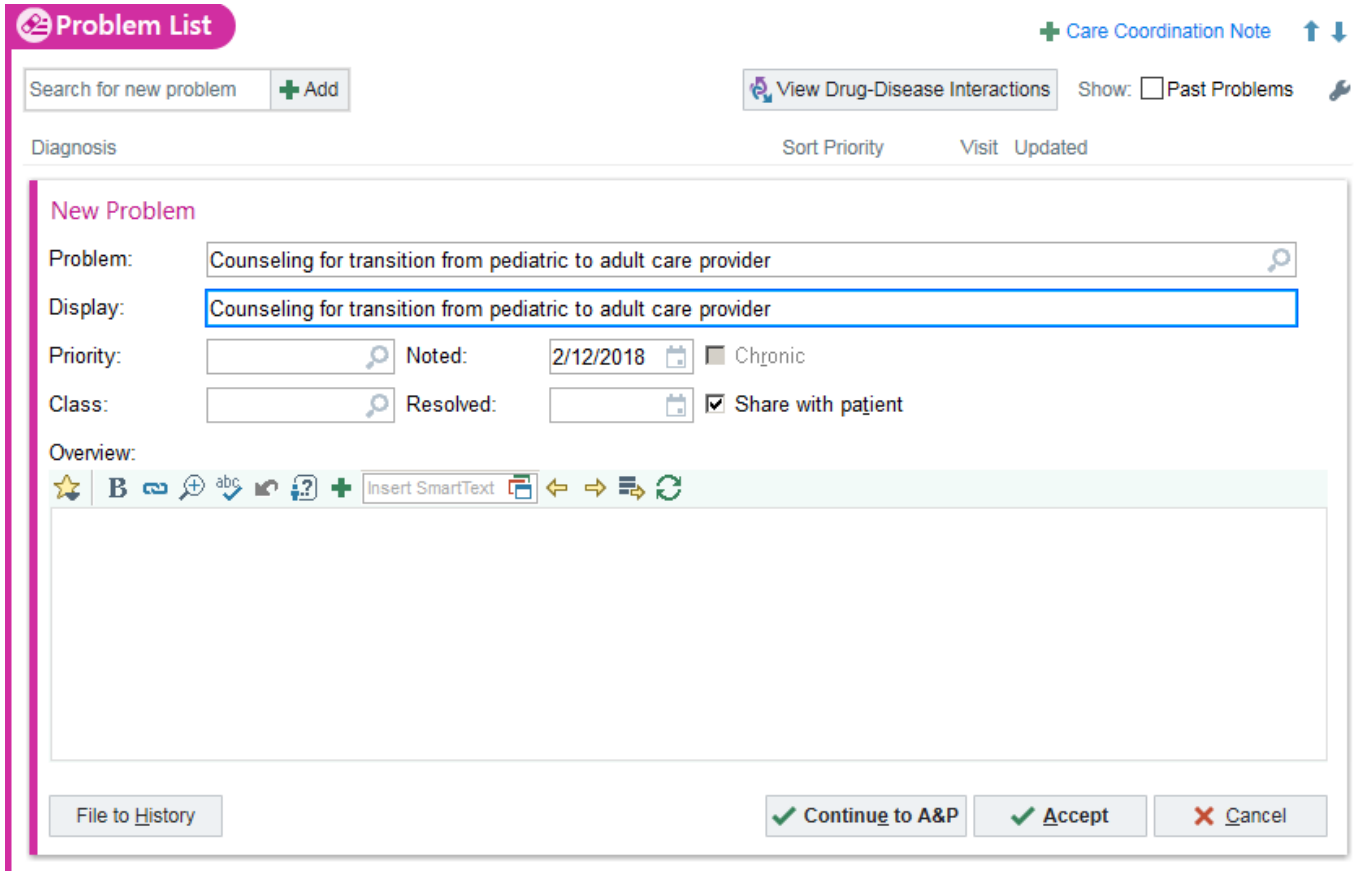
Problem List
Care Coordination Note
Search for new problem
Add
View Drug-Disease Interactions
Show:
Past Problems
Diagnosis
Sort Priority
Visit
Updated
New Problem
Problem:
Counseling for transition from pediatric to adult care provider
Display:
Counseling for transition from pediatric to adult care provider
Priority:
Noted:
2/12/2018
Chronic
Class:
Resolved:
Share with patient
Overview:
Insert SmartText
File to History
Continue to A&P
Accept
Cancel

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PACT Starter Kit

PEDIATRIC TO ADULT CARE TRANSITIONS (PACT) STARTER KIT

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OHSU DOERNBECHER CHILDREN'S Hospital

1. BUILD YOUR TEAM

Champions are needed
Involve all team members – interprofessional effort

2. SET GOALS AND TIMELINE

Many points of intervention - consider when to initiate and follow up with patients
Will depend on clinic bandwidth and priorities
Communication is key

3. DECIDE...

WHICH PATIENTS YOU WILL TARGET

- Healthy, typically developing adolescent
- Adolescent with chronic health condition but no cognitive impairment
- Adolescent with significant cognitive impairment requiring lifelong assistance with care and decision making

HOW YOU WILL INTRODUCE PROGRAM TO PATIENTS AND FAMILIES

- Letters, handouts, phone outreach
- Face to face visits

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Now it is your turn!

- Think about your clinical setting
- Take out a sheet of paper and write your next 2 steps
  - Who to talk to, who is your team?
  - Where will you collect resources?
  - What baseline information will you collect?
  - What can you start trialing next week?

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Summary

- Process can seem overwhelming
  - Lots of steps
  - Lots of variables

- Start the process early (age 12-14)

- Bring a group together and start with your ideas

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Review Objectives

- Identify available resources for creating a transition program
- Review the Pediatric to Adult Transition (PACT) Starter Kit
- Create an outline for your own clinic transition process

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Thank You

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