

CHA Youth to Adult Transition

Team Members

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Transition Readiness Tool

4. Looking ahead to the next 6 months, please rate your **understanding** of the next steps in the pediatric to adult transition process for your child. Drag the red dot to select your answer.

No understanding Full understanding
0 1 2 3 4 5 6 7 8 9 10



5. Please rate your **confidence level** for taking the next steps in the pediatric to adult transition process for your child. Drag the red dot to select your answer.

Not at all confident Fully confident
0 1 2 3 4 5 6 7 8 9 10



6. Please rate your **overall understanding** of the pediatric to adult transition process. Drag the red dot to select your answer.

No understanding Full understanding
0 1 2 3 4 5 6 7 8 9 10



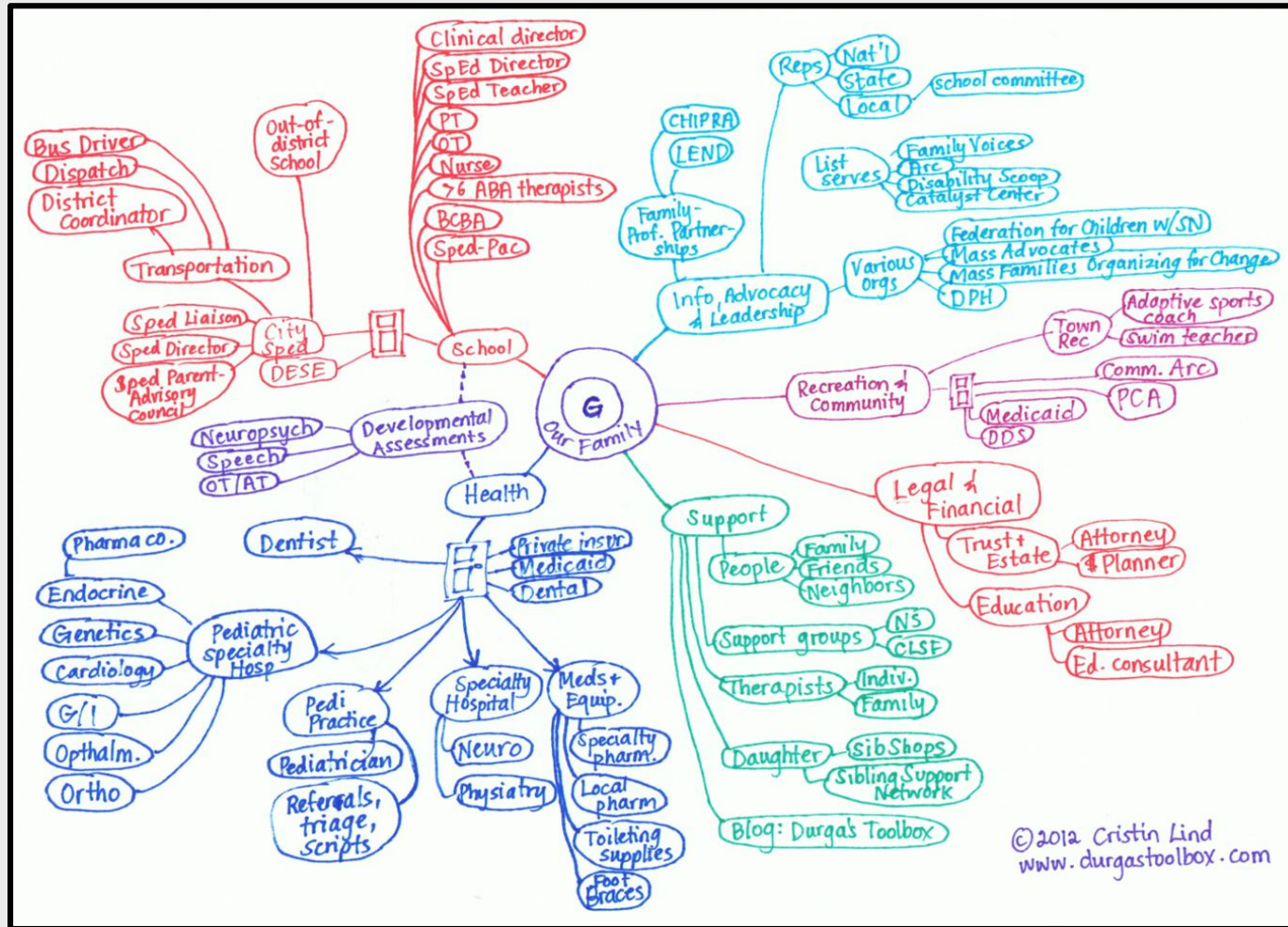
Weekly Transition Discussion with Team

This year we listed and reviewed all upcoming transition-age visits on our weekly team agenda. This reminder served to:

- 1) Increase the use of the Transition Checklist by providers
- 2) Promote discussion of specific family needs and concerns with regard to transition



Care Mapping Workshop



Tim Markle, MA, MA/CS

8 parents from PCCP

June 17th, 2020



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EMR Transition Checklist

PEDIATRIC TO ADULT TRANSITION CHECKLIST

PRESS "F3" TO MAKE EASIER TO SEE

Task	Provider Name(s)	Dates	Comments (brief)
Early Teen (Suggested Ages 12-13)			
<i>Family has received all age/developmentally relevant material on transition (topics below)</i>			(Y/N)
Introduce transition topic to teen/family			
Discuss confidentiality with teen/family. Allow 1 on 1 time with teen during visit			
Middle Teen (Ages 14-15)			
<i>Family has received all age/developmentally relevant material on transition (topics below)</i>			(Y/N)
Explain how to access healthcare after hours / on weekends, during weekdays			
Discuss what "healthy" means?			
Include independent time during visits			
Late Teen (Ages 16-17)			
<i>Family has received all age/developmentally relevant material on transition (topics below)</i>			(Y/N)
Discuss post high school plans			
Assess insurance knowledge / coverage after adulthood			
Set expectations of hospitalization			



Teen After Visit Summary

Late Teen (16-17 years old):

Depending on your child's abilities and developmental readiness, we will (with either you, your child or both) ---

- Talk about how to make appointments, why it's important to go to appointments, and what to do when you get sick or have a health problem.
- Teach them about what medicines they take and why, as well as how to order their medicines and supplies.
- Talk to them about their post-high school plans, including extended individualized education plans (IEP).
- Discuss educational and work experiences they might like to pursue.
- Help them start thinking about future adult housing choices.
- Discuss and prepare them for changes that happen after they turn 18. These can involve changes in health insurance coverage, income and benefits, where they get hospitalized (children's vs university hospital), which providers they see (child vs adult specialists), release of information authorizations, MyChart access, and supportive decision making/advance directives/guardianship arrangements.
- Connect your family with a social worker to prepare for some of these changes.

Helpful resources for this age group:

Waisman transition toolkit: <https://www2.waisman.wisc.edu/cedd//pdfs/products/health/THCL.pdf>

ADRC website: <http://www.daneadrc.org/>

Youth Health Transition Initiative: <https://healthtransitionwi.org/>



Who Am I? Form



**Hi! I am Mitchell. I liked to be called Mitch.
I am 16 years old.**

People who are important to me:

- My mom, Jane
- My sister, Becky
- My nurse, Lisa

People who help me make medical decisions:

Legal guardian: my mom, Jane Smith, 608-231-5555
Others: My grandma, Maple Smith, 564-677-3632

Things that make me happy or calm:

- This Old House show
- My dog, Rusty
- Popsicles
- Family being nearby
- Singing

Things that upset me:

- Loud noises
- Needles
- Lots of people in the exam room
- Bright lights in my eyes

Routines that are important to me:

- Sensory breaks
- Sipping water with my medicine
- Nightlight at night
- Going to school as much as possible

Things that I am really good at:

- Making my family smile
- Taking walks in my neighborhood
- Watching my dog chase a ball
- Listening to my sister sing
- Building with Duplos

My caregivers assist me with:

- Doing my respiratory treatments
- Feeding me

Things I (or my parents) prefer to do:

- Bathing me
- Dressing me
- Getting me ready for bedtime

What I'm working on:

- toileting
- learning about my medicines
- telling people what I need
- expressing my feelings

The best way to communicate with me:

- Talk slowly and repeat instructions
- Ask me yes/no questions
- Speak directly to me



Goal Cards - Teen Subset

Goal Area	Card
Communication	<ul style="list-style-type: none">• Learn how to tell others what I need
Independence	<ul style="list-style-type: none">• Accept my differences• Be more independent
Community, Social, School	<ul style="list-style-type: none">• Experience my community• Make my own decisions• Be part of my school
Medical Health	<ul style="list-style-type: none">• Make the switch to adult healthcare system• Learn how to use my equipment/supplies• Learn about my medications



Goal Card Examples



Have transportation I use with my family



Experience my community

The English version of the goal cards can be found here: <https://go.wisc.edu/61snzj>



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Parent Interviews

- What part of the transition process has been completed?
- Were you satisfied with the transition process? What went well? What could have gone better?
- Were there any obstacles or stumbling blocks you didn't anticipate? If yes, how did you overcome them?
- What advice would you offer other providers/self-advocates/caregivers beginning their transition journey?



Patient Interview Demographics

- 14-year-old, currently enrolled, beginning phase of the transition process
- 15-year-old, currently enrolled, middle phase of the transition process
- 15-year-old, currently enrolled, middle phase
- 17-year-old, currently enrolled, pre-transition phase
- 19-year-old, graduated from PCCP, post-transition phase



Parent Interview Themes

- Families:
 - Expressed gratitude for the services PCCP offers
 - Felt supported by the PCCP team
 - Were satisfied with the discussions and information received
 - Have trepidation about transitioning to the adult world
 - Felt a sense of community and validation in knowing they weren't alone during the process; both in relation to PCCP team support and in relation to other families going through the process



Parent Interview Quotes

- “The PCCP team did a good job discussing transition...They help you along the way.”
- “It’s nice that they introduce it early so we have time to think about it.”
- “It doesn’t feel like you will be pulling the carpet out from underneath us.”
- “The PCCP team is comforting and familiar.”
- “It’s intimidating for parents to make the leap from peds to adult since they are supported so well by the Complex Care Program.”
- “The adult side just does things so differently. You are scattered at different UW facilities.”
- “The adult side should be prepared to ‘catch the ball.’”



Parent Interview Suggestions

- Continue having candid discussions
- Create a Y to A transition folder
- Include family experiences and input
- Highlight positives of the adult world
- Continue collaborative work for smooth Y to A provider handoffs



Remaining Activities for 2020

- Conduct EMR audit of transition activities for patients 12 years and older
- Incorporate parent feedback from interviews



Thank you!

Questions?



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