Transition to Adult Care – Lessons Learned

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Complex Care Program (CCP)

- Our patient population
  - Criteria for CCP: 3 organ systems (requiring specialty care), 10 clinic visits/year OR 5 inpatient days/year (unplanned)
- Program structure
  - Each patient is assigned a Care Coordination Assistant, Nurse Case Manager, and Provider
  - What we do
    - Care coordination and medical co-management
    - Creation of SPoCs
    - Monthly check in calls (medical status update, community resources, equipment/supply needs)
    - 24/7 Urgent on call line
    - Clinic visits every 6 months (reviewing medical status and community resources)
    - Daily inpatient rounding (consultative service) on patients who are admitted in the hospital
    - Collaboration with specialists, schools, community agencies and other stakeholders

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Transition – Initial State

Patient Education Materials

- 2019
  - Organizational policies/tools not consistently being utilized
    - Transition Policy
    - Transition Checklist in EPIC
  - Our focus:
    - Creation of dot phrases
    - Outlined a list of topics/needs to be discussed at different ages

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Dot Phrases

12-14

- Start thinking about where you would want to transition health care to (closer to home, in Milwaukee area, etc)

14-16

- Choose what location/health care system you would want to transition to.
- Ask your pediatrician how long they will continue to follow you and if they have recommendations for an adult primary care provider.
- Start talking with your specialists about transition.
- Ask school about transition coordinator and request transition plan. If home schooled, contact regional center for guidance.

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Dot Phrases

16-18

- Identify what location/health care system you would want to transition to and get connected with an adult primary care provider.
- Ask current specialists for recommendations for adult specialty providers.
- Ask school about transition coordinator and request transition plan if not already in place. If home schooled, contact regional center for guidance.
- At **17 years and 6 months**, apply for guardianship or supported decision making. If you have questions, please contact the regional center or ask your child's social worker.
- At **17 years and 6 months**, consider connecting with your local aging and disability resource center (ADRC). You can receive more information at the regional center.

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Dot Phrases

18+

- Ask current specialists for recommendations for adult specialty providers if not already completed, and ask when the last visit will take place.
- Start attending appointments with adult primary care provider and specialists.
- Ask school about transition coordinator and request transition plan if not already in place. If home schooled, contact regional center for guidance.
- If guardianship or supported decision making has not been done, please contact the regional center or ask your child's social worker for help.
- Consider connecting with your local aging and disability resource center (ADRC). You can receive more information at the regional center.

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Patient Education Materials

- 2020
  - Utilizing dot phrases in AVS– improving compliance within our group
  - Ongoing education with group regarding topics to discuss with families
  - Transition column in SPoC
  - Dreaming Differently
  - Next steps:
    - Transition checklist in EPIC – more user friendly for different populations
    - Family friendly tools
      - Stepping stones

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Transition Insights

- What went well
  - Colleagues are open and willing to learn about transition and explore tools that could be used
  - Having transition conversations with families earlier
  - Creating a transition culture
  - Identified workflow within CCP
  - Having “point people” to ask for help regarding transition

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Transition Insights

- Areas for improvement
  - Continued compliance challenges with dot phrases
  - Buy in from other specialists and organization
    - What is the right forum?
    - Creating tools not processes
    - Minimal representation from specialties
    - How do we get multiple disciplines at the table?
  - How do we form relationships with adult providers?

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Hopes and Dreams

- Readiness assessment – revision and implementation
- Institutional approach
- Increased family engagement regarding transition process
- Form relationships with adult providers
- Interview families/patients previously in CCP who have transitioned
  - What went well?
  - What went poorly?
  - What do they wish they would've known?

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