



Supporting Children with Special Health Care Needs from childhood and adolescence through adulthood

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Desired outcomes of the transition beyond pediatrics

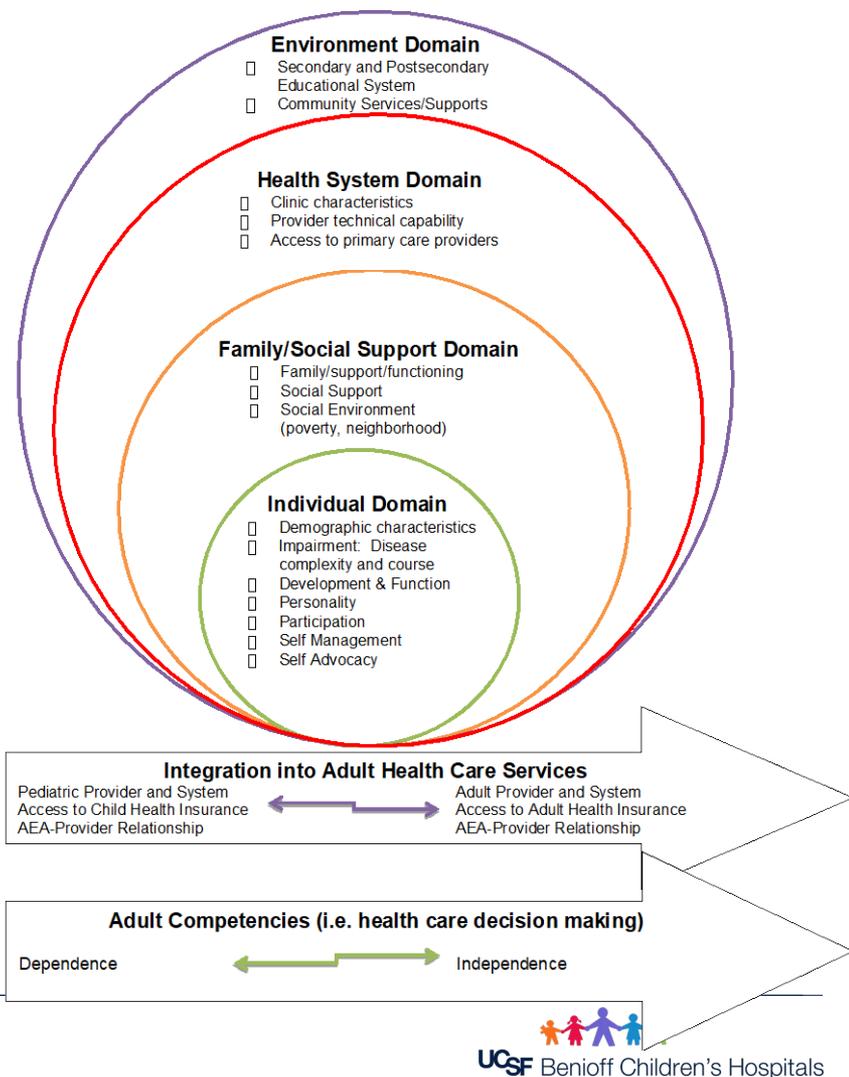
“We have kids that are severely, multiply disabled but they live at home and they’ve grown up in being part of their community. They were not institutionalized folks. These are people that lived in families, went to church, went on trick or treating with their neighborhood kids and family members and they’re still in their community and we want them to stay in their community and we want them to live at home. We want them to still be participatory in their community so how do we do that?”

-Mother

What's the Problem?

- Many adolescents and young adults struggle with life beyond the “pediatric system” with subsequent poor outcomes
 - Educational Attainment
 - Vocational Attainment
 - Social Engagement
 - Disease Management
 - Disease Outcomes

Improving health and outcomes of children through adulthood needs an ecological approach



How do we address the Problem?

But you know not every parent is like me. I was lucky because I was well-educated, and you know I'm aggressive and I'm a good advocate for my kids. What about parents who can't speak and do things for their kids? How are the kids going to get help?

-Mother

Populations at risk; each require a different “system” of care and approach

- Children with Special Health Care Needs
 - Intellectual and Developmental Disability (Autism, Down Syndrome)
 - Exit out of school-based supports
 - Does someone “age out” of the need to develop and learn? What supports should be given for those who are still developing and learning?
 - No alignment of Developmental Pediatric services within the adult health care space
 - Behavioral and Emotional Health (Depression, ADHD)
 - Behavioral and Mental health supports
 - School-based supports

Populations at risk; each require a different “system” of care and approach

- Children with Special Health Care Needs
 - Chronic Medical Conditions (Asthma, Diabetes, Cystic Fibrosis, Sickle Cell Disease, Inflammatory Bowel Disease)
 - Ensuring self-management and management of disease management burn out
 - Physical Disabilities (Cerebral Palsy)
 - Ensuring physical access (American with Disabilities Act)

Special considerations

- Racial and Ethnic Minorities
 - Significant barriers to engagement in health care and research participation
 - Systemic bias (Sickle Cell Disease and pain medication)
- Children Living in Poverty
 - Access to resources, “Social Capital”
- Gender Considerations
 - Reproductive health
 - Needs of LGBTQ and gender non-binary

Special considerations

- Children who have immigrated to the United States
 - Language barriers and adapting to new culture
 - Child health issues developed from countries of origin (trauma, war, famine, differences in access to child healthcare)
- Regional considerations
 - Regions differ in resources (e.g., rural communities) and may not have access to all medical treatments or health supports
 - specialized medical services
 - Physical/occupational therapy

Supporting families and youth in their journey

- How do parents know what resources are available for CSHCN?
- How do we best ensure equity of services for CSHCN and their families?
- How do we best support children to attain the appropriate skills to maintain health and wellness while navigating across different systems as they age out of programs

Closing Thoughts

- Ensuring a life course approach to health to children with special health care needs is the rising tide that can improve care
- Develop measures and research that support childhood/adolescent interventions that also promote longer-term "success" in adulthood.
 - Family and patient engagement
- Ensure work done impacts **both pediatric and adult systems of care** to ensure the highest level of quality of care and life for children and adults with special needs.

References

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