



April 24, 2025

Health Transition Learning Community

# Lessons from the Field: Insuring Improved Healthcare Transition for Wisconsin's Survivors of Congenital Heart Disease

Please sign in by writing your name and organization in the chat box.

To join the Health Transition listserv, please include your email address.

# Tips for a successful experience in today's call

- Please mute your line.
- Presenters will take questions during and at the end of the presentation.
- Feel free to type questions in the chat box at any time.
- During Q & A, if you want to ask a question, raise your hand or just unmute yourself and speak.

*Please type your name and organization in the chat box.*

# STARTING FROM THE HEART

## Insuring Improved Healthcare Transition for Wisconsin's Survivors of Congenital Heart Disease: Lessons from the Field

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Pediatrics, Division of Cardiology  
School of Medicine and Public  
Health, University of Wisconsin,  
Madison

**YHTI Learning Community**  
**April 24, 2025**



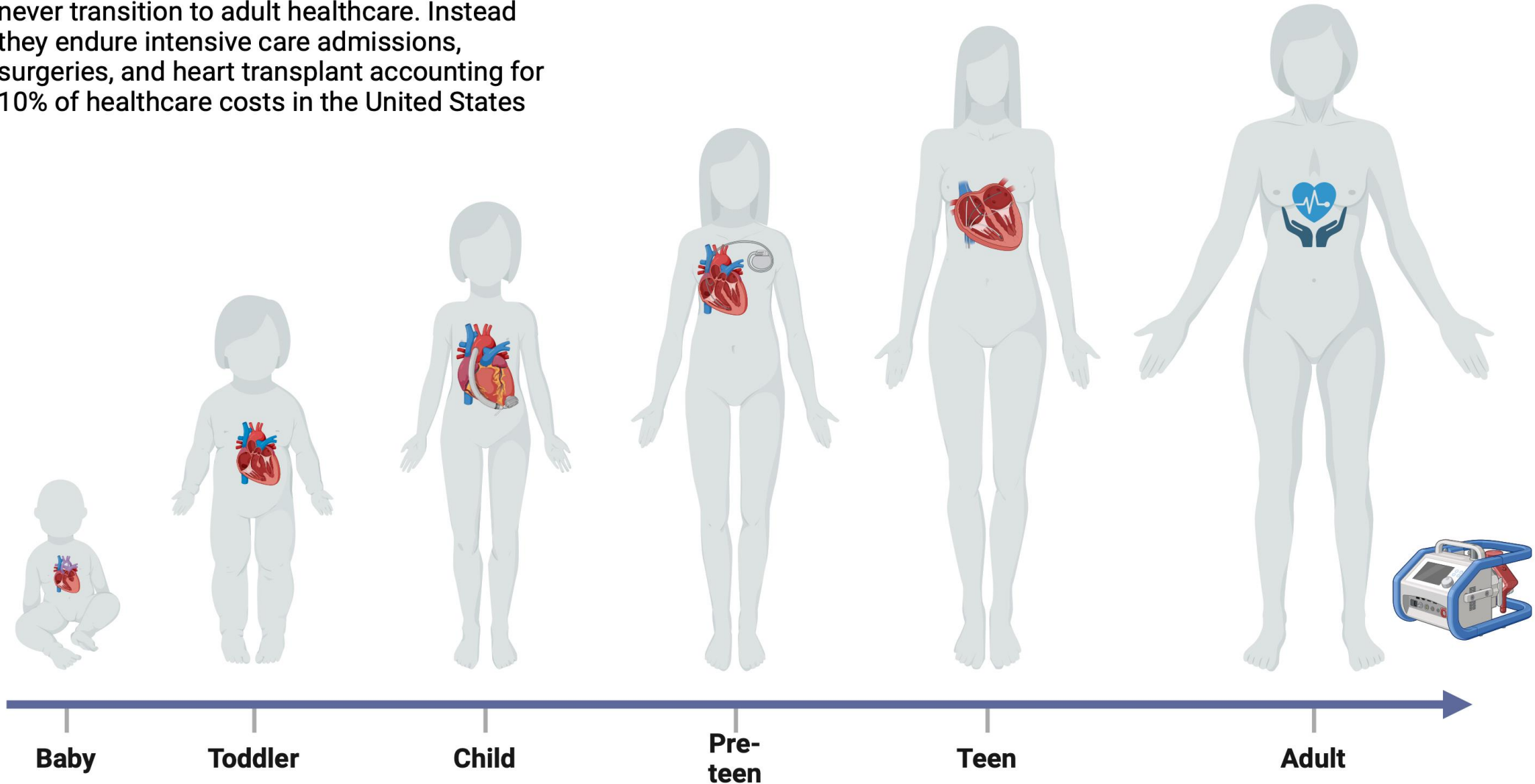
**WISCONSIN**  
UNIVERSITY OF WISCONSIN-MADISON

# By watching this presentation, you will be able to:

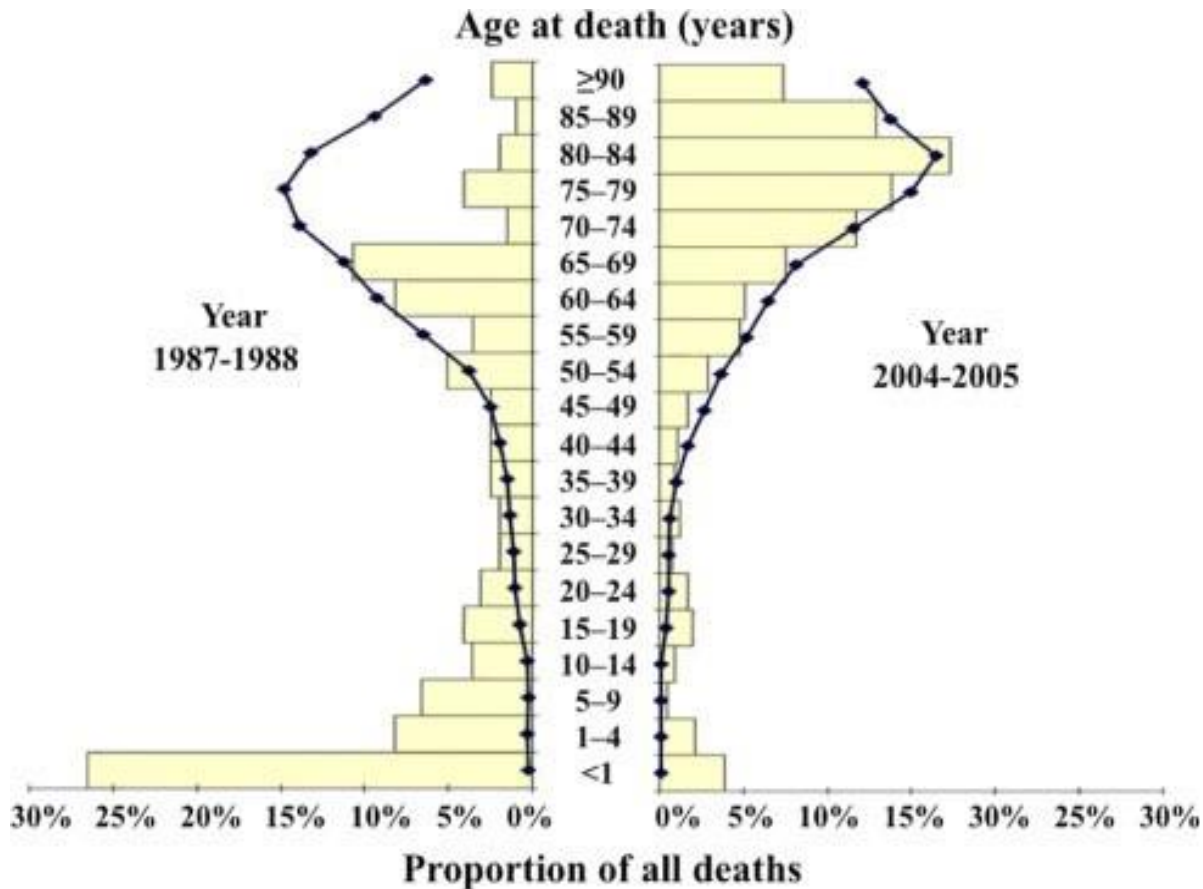
1. Describe known healthcare transition disparities in adolescents with Congenital Heart Disease (CHD) and disabilities,
2. Learn how a transition readiness assessment for adolescents with CHD and disabilities was used to guide healthcare transition education,
3. Identify elements of accessible healthcare transition interventions, and
4. Describe plans for the HEART-WISE project to assess Wisconsin Medicaid enrollment patterns, health care utilization, and the impact of policy on CHD survivors.

## 1 in 100 children are born with congenital heart disease, 97 now survive to adulthood

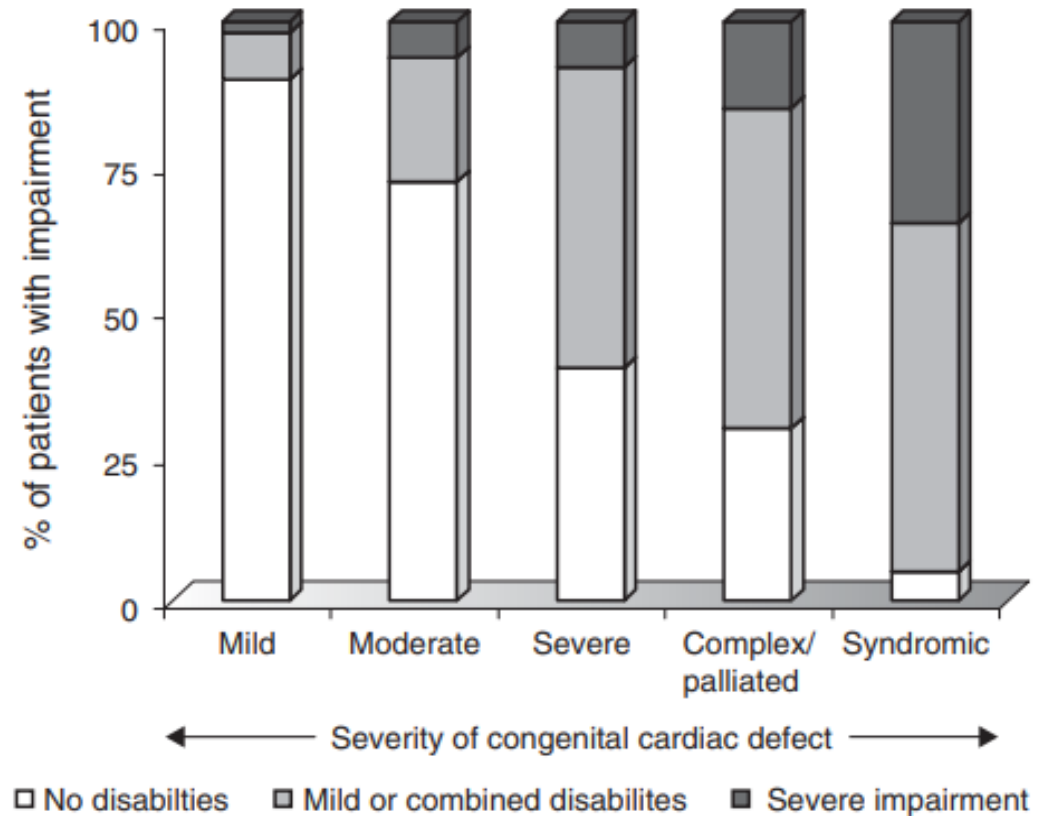
They need lifelong care but more than half never transition to adult healthcare. Instead they endure intensive care admissions, surgeries, and heart transplant accounting for 10% of healthcare costs in the United States



# Surviving with Disabilities



Khairy et al (2010) JACC 56(14):1149-1157



Wernovsky (2006) Cardiology in the Young 16(S1):92-104



Pediatric and Adult Congenital Heart Program

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SCHOOL OF MEDICINE AND PUBLIC HEALTH



# Our Team



Accessible **CHD** Survivor Transition Readiness For Long-Term Health (**ACHD STRONG**)

Insuring Improved **Healthcare** Transition for **Wisconsin's** Survivors of Congenital Heart Disease (**HEART-WISE**)



Difficulties transitioning without an accessible care model.

*\*Maria is the name assigned to a composite case description to protect participant identity.*

## How Families Make Medical Care Work

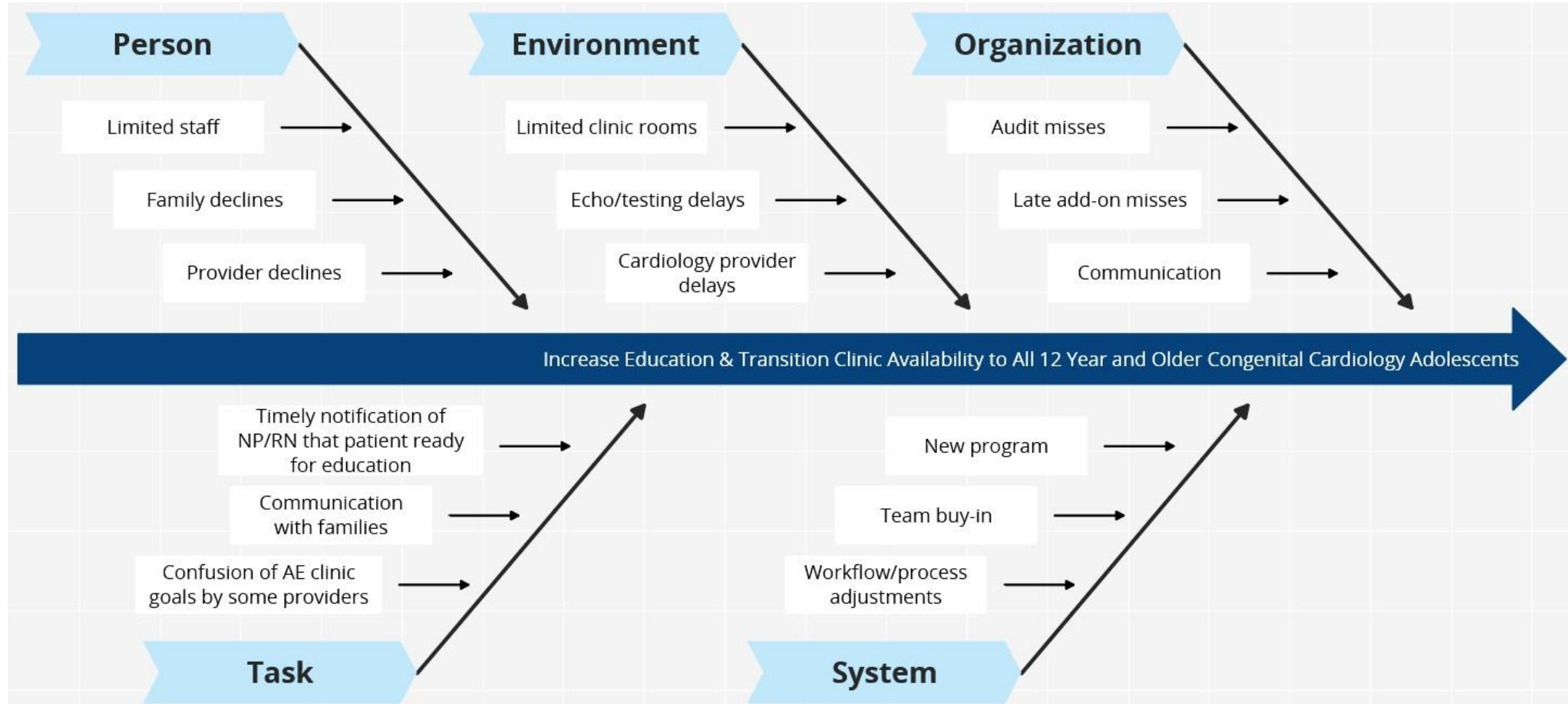
“Can we talk about applying for disability, where to go to apply, when to seek out a lawyer, and any words of wisdom? My [child] with congenital heart disease is autistic. [They] just turned 19. So, Katie Beckett [Medicaid waiver program] is done. But [they] qualified for Family Care....

My big concern is that [they] lose our military insurance at age 21 if not a full-time student. So that’s the push to get the disability process going from my perspective....”

*Mother of a young person with critical congenital heart disease (in an interview with Dr. Olson for ACHD STRONG)*



# Healthcare transition in congenital heart disease



# Health disparities for patients with disabilities, females

Transition  
Readiness  
Assessment of  
CHD measures a  
patient's level of  
confidence in  
transition,  
knowledge of their  
health, and health  
care usage

	Subjects w/o disabilities (N=98)			Subjects w/ disabilities (N=54)		
	Males	Females	P value	Males	Females	P value
Confidence in taking care of heart care*, mean (SD)	6.1 (3.1)	5.0 (3.7)	0.234	7.5 (2.5)	5.2 (3.7)	<b>0.011</b>
I know I need life-long heart care from a congenital heart disease specialist, N (%)	43 (93.5)	31 (73.8)	<b>0.023</b>	24 (88.9)	17 (77.3)	0.429
I know what to do in case I have a medical emergency, N (%)	39 (84.8)	37 (88.1)	0.651	26 (86.7)	13 (59.1)	<b>0.023</b>
I have a paper or electronic file for my medical information, N (%)	23 (51.1)	22 (52.4)	0.906	18 (60.0)	6 (27.3)	<b>0.019</b>
I carry important health information with me every day, N (%)	23 (51.1)	13 (31.0)	0.056	18 (60.0)	7 (31.8)	<b>0.044</b>

\*range 0-10, with a higher score representing more confidence.

Bolded values represent significance at the 0.05 level.



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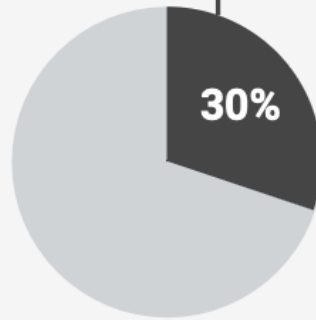
Olson KR, Swanson BL, Zhang X, Allen CC et al. "Closing the Survivorship Gap for Women with Congenital Heart Disease," *Journal of Women's Health* 2024

Prior research doesn't reflect the population today

## PROBLEM WITH EXISTING MODELS OF HEALTHCARE TRANSITION

**Do not account for disability**

Communication, mobility, and cognitive differences



Clinical tools and interventions have been designed for survivors without disabilities



And take a life stage approach that does not account for social support needs

# Our initial sample came from a database of 796 patients

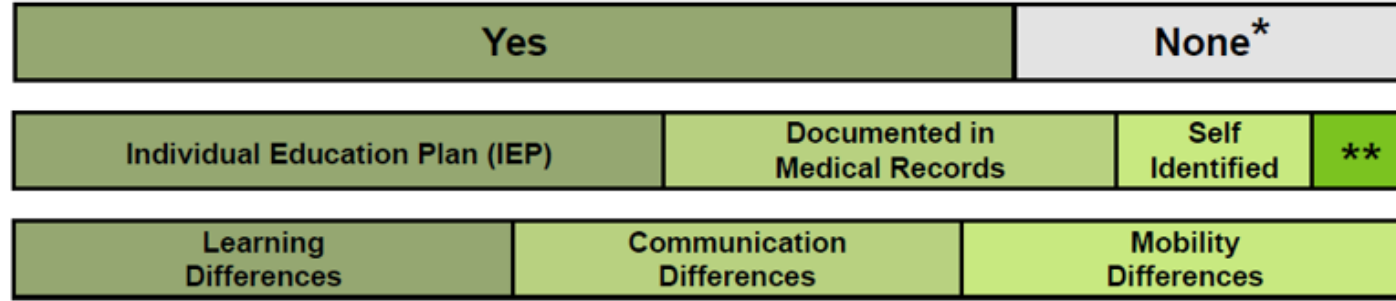
\*nearly all participants had documented anxiety or depression diagnoses

\*\*self-identified, not documented in the medical record

\*\*\*population experiences family changes, frequent moves, migration, foster care, or death of a primary support person

\*\*\*\*extended absences or withdrawal from school

## Disability



## DESCRIPTIVE CHARACTERISTICS OF PRIOR TRANSITIONS

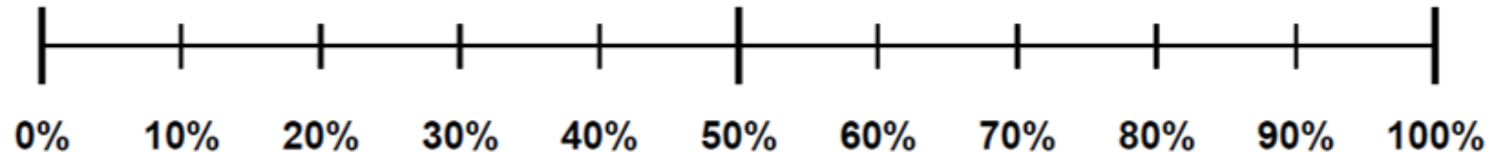
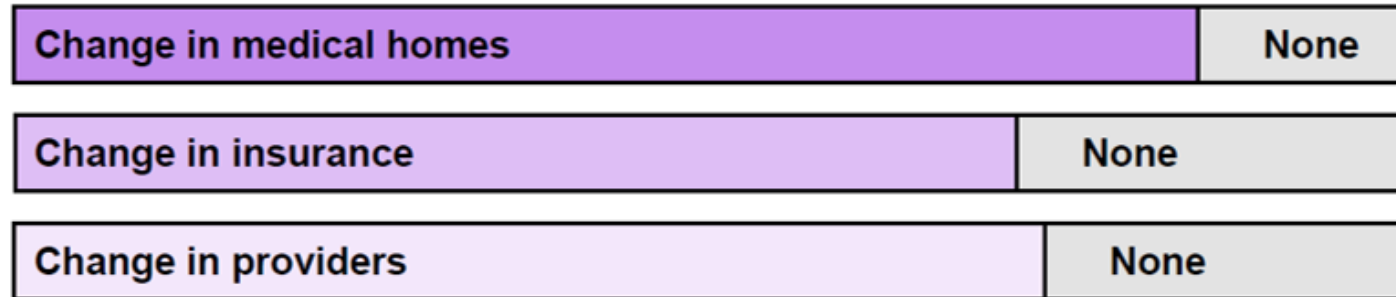
### Social Support



### School



### Medical



Olson, K., Swanson, B, Allen, C et al. "A Community-Based Conceptual Model for Transitioning Youth with Congenital Heart Disease," *Pediatric Academic Society*, 2024



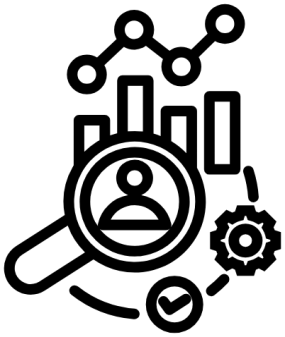
# Formative research 2021-2024



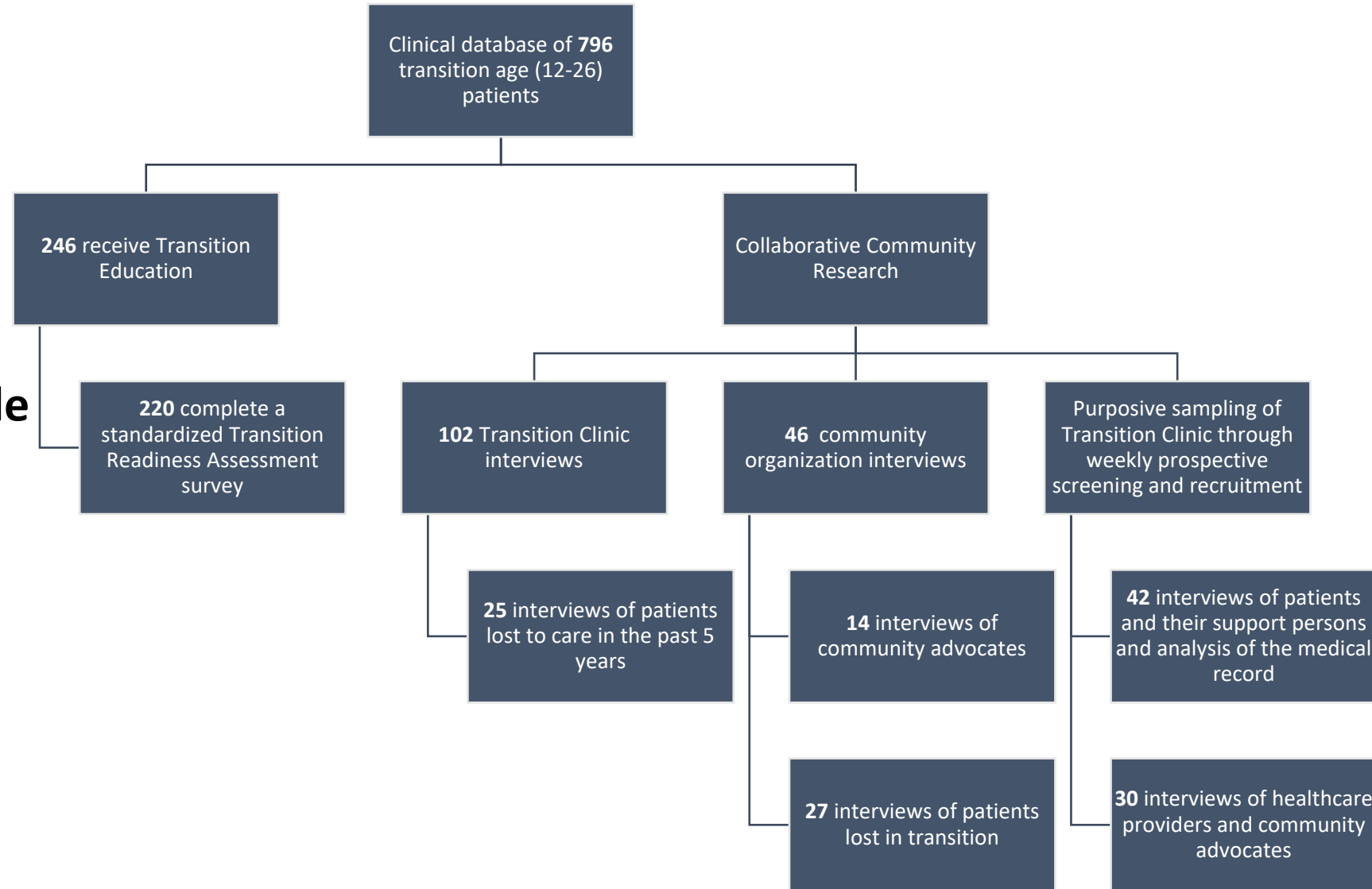
**220 interviews**



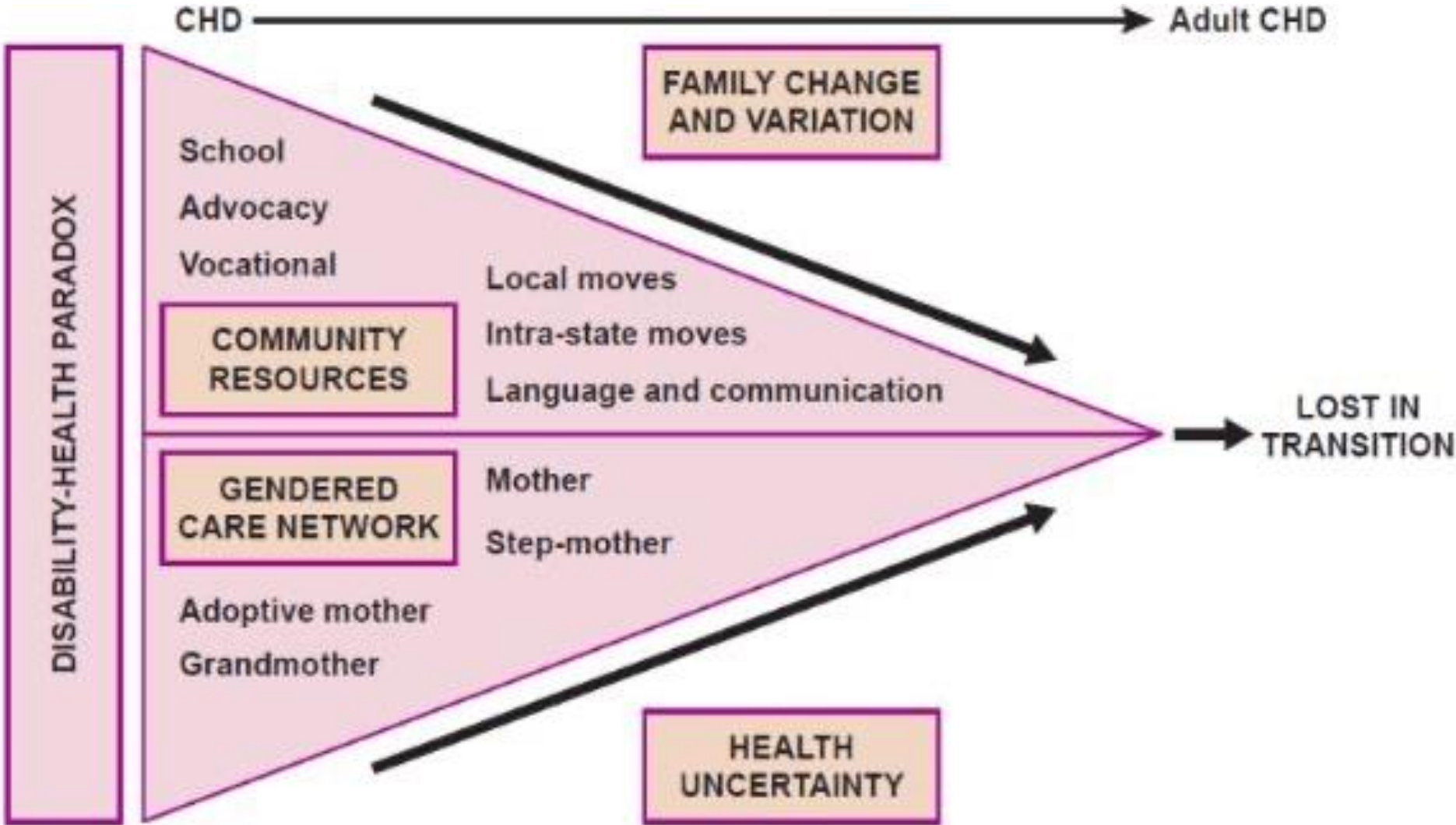
**150 interviews  
inclusive of people  
with disabilities**



**Mixed methods  
analysis of a 796  
patient database**

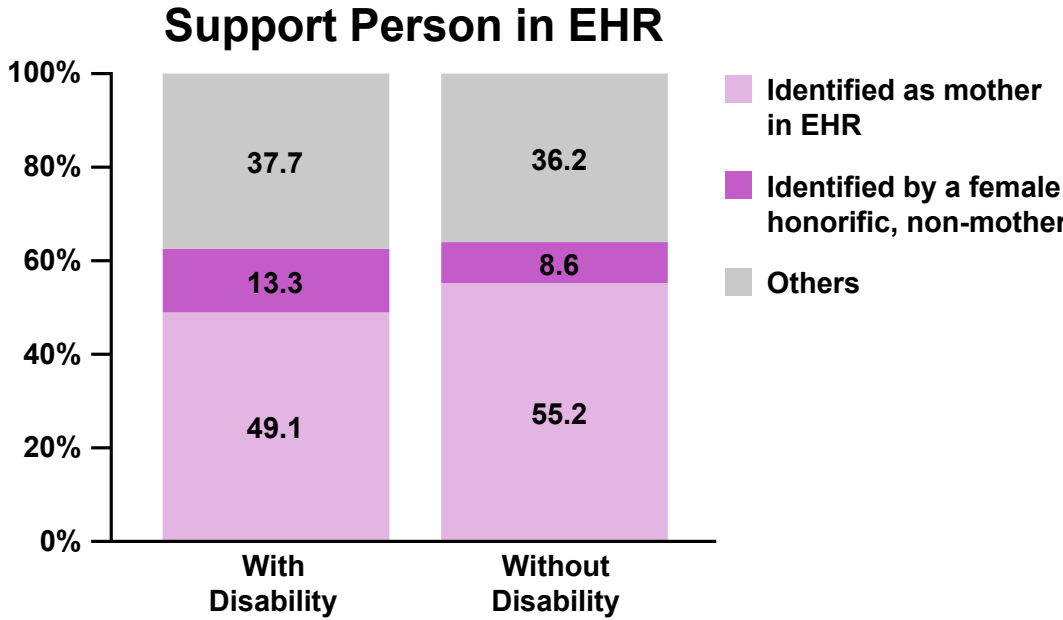
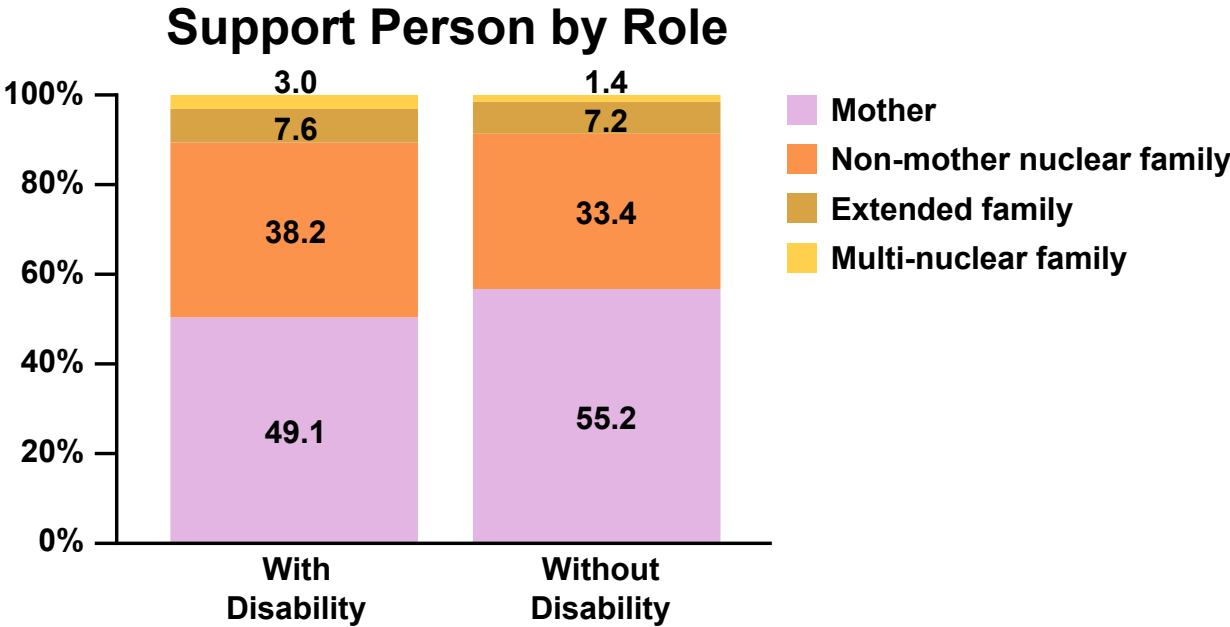


# Narrowing support over the transition period



Olson, K., Swanson, B, Zhang X Allen, C et al. "Gender Differences in the Care Network of Transition Age Youth with Congenital Heart Disease," *Journal of Women's Health*. 2023

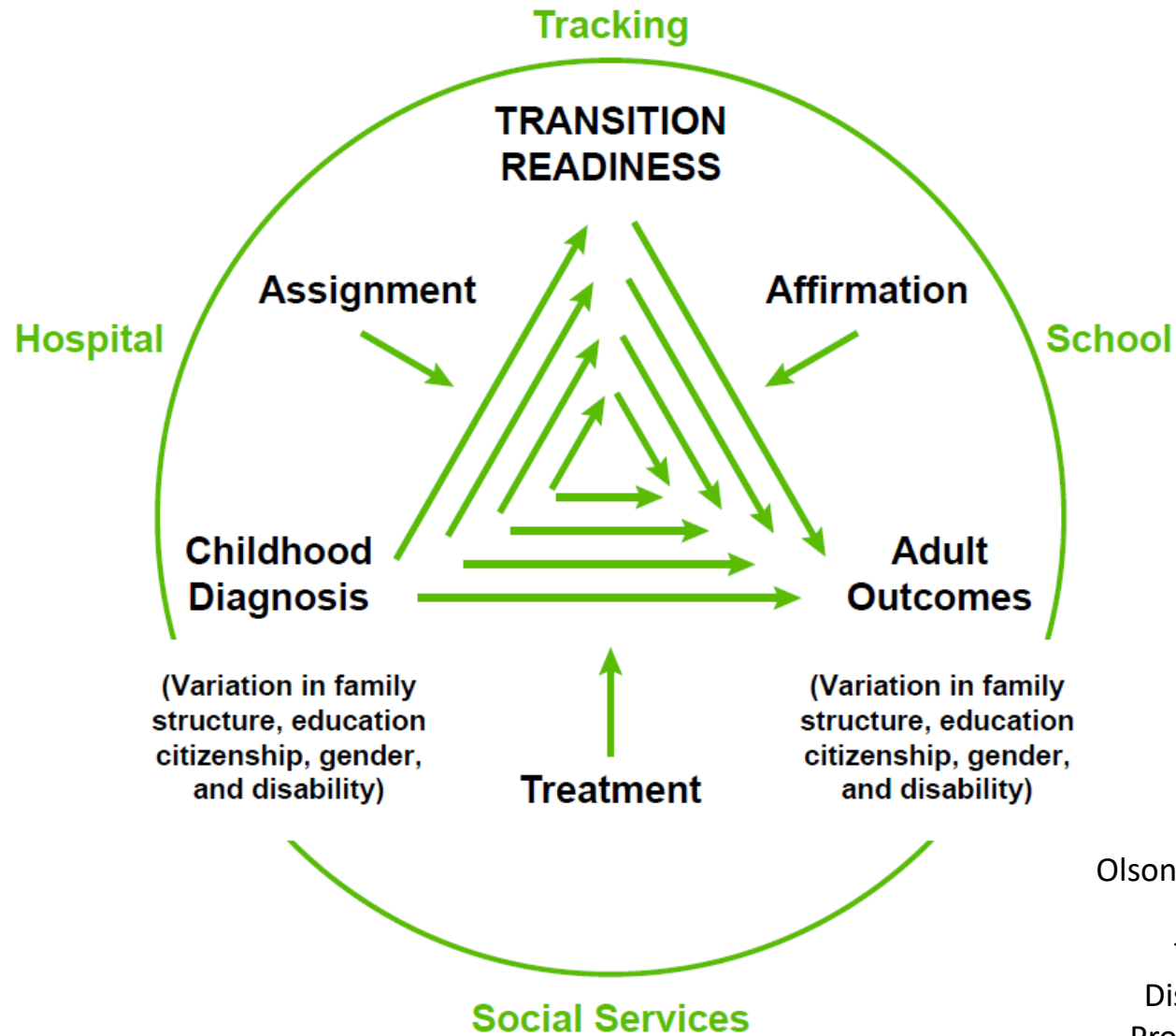
# The social network in patient medical records



Only patients with disabilities had care networks led by non-mothers.

Olson, K., Swanson, B, Zhang X, Allen, C et al. "Gender Differences in the Care Network of Transition Age Youth with Congenital Heart Disease." *Journal of Women's Health* 2023

# Address hospital, school and insurance silos



Olson, K., Swanson, B, Cao, J, Zhang X, Allen, C. et al. "The Social Context for Mental Health in Transition Age Patients with Congenital Heart Disease: Insights from Individuals, Families, and Providers," *Healthcare Transitions*. Under review



**We  
created  
new tools  
to  
provide a  
roadmap  
for  
patients**

### **Initial Transition Readiness Assessment**

- Measures confidence and knowledge
- 21-item tool for clinical assessment of health knowledge and navigation skills



### **Adapted Transition Readiness Assessment**

- Conversation starter for youth and families to invest in health awareness
- Highlights the need for life-long specialized heart care
- Recognizes youth at risk during transition
- Measure the patterns and intensity of support needed for transition
- 24 item tool using the Supports Intensity Scale® (child or adult version) with a risk stratification score for providers
- Youth and providers prioritize areas of interest over time
- Digital accessibility in plain language with graphics
- Designed with patients, caregivers, providers, and community advocates targeting local resources



**To make  
sure their  
questions  
are  
answered**

# Health Care Planning with your Cardiologist

Planning health care can be difficult when you are born with a heart problem. That's why some young people with heart problems and their families used their experiences to make these questions.



## **How can I plan for my future health needs?**

How does my current health factor into future plans?

What is likely to happen when I transition from pediatric to adult care?

What if I don't transition?

Can you tell me about any specialized care I will need as I get older?



## **What is expected over time?**

How do you think daily life will look as I get older? (In three months, one year, five years, ten years)

Will I need any procedures or surgeries?

Will I need school or community supports?

Will it impact my work or job?

How will my heart history affect my health over time?

When I'm older, what type of care do you think will be needed?



## **What happens if there are problems?**

Can you describe any serious problems that might occur and explain what those mean for me?

If I cannot communicate, how can I share my health information and wishes?

If we decide to have someone support me in making medical decisions, what do we need to do to make those arrangements official?

If my needs increase, what resources are available to me?











“....I’m a high schooler...and I was born a disabled person....I was also born with hearing loss, and I have a record of surgeries.” *[early teen patient, moderate cardiac disease, urban when asked for an introduction]*



Description: Young boy in hospital bed,  
sternotomy scar visible  
scar visible, has his device checked  
with a Mag flashlight

“It doesn’t get easier when your kid has procedure umpteen-hundred. The anxiety compounded by the night’s tornado warning and lack of sleep only added to the adventure.

And she still managed the fear and explanations like a rock star. She woke from anesthesia as her usual delightful self. We also needed to begin our breakfast routine at 4:30 am to finish in time to give 8 hours before the procedure.

....And thanks to help and supports from a few friends, it all went pretty smoothly.” *Middle aged mother to a young person with critical congenital heart disease*

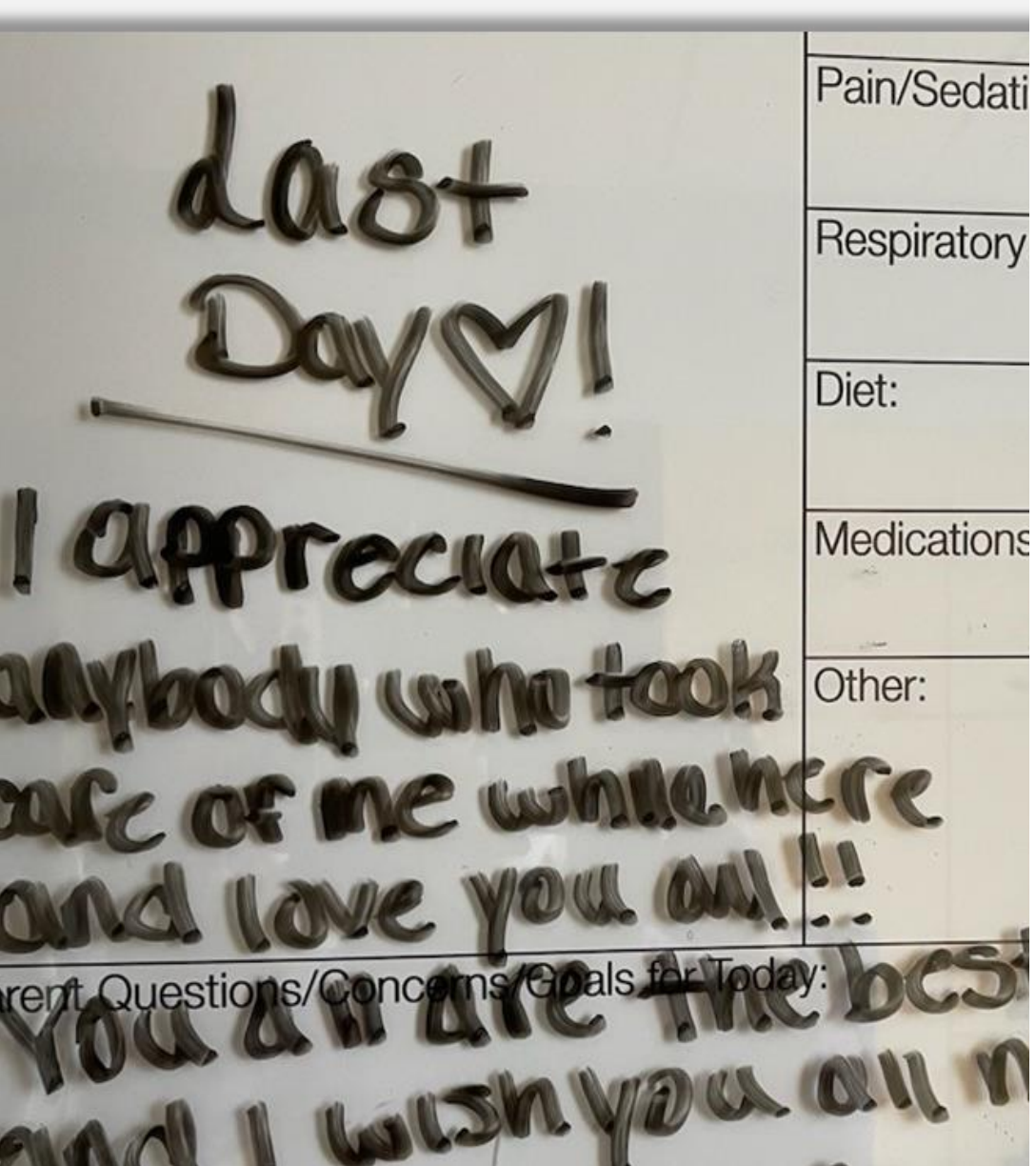


Image description: Handwritten note of appreciation on a glass board in a hospital room

—

“What we absorb as our own responsibility because social, educational, economic and medical structures fall well short. Others, not impacted by these things do not prioritize them. Not when they vote, or what they advocate for...

Caring for a loved one is an honor and a visceral, tangible, embodied, even ritual way to get to love someone. Without a doubt.

The literal act of love is constant. That is a grounding thing.

It only becomes challenging and even burdensome when we are left by friends, family, systems.

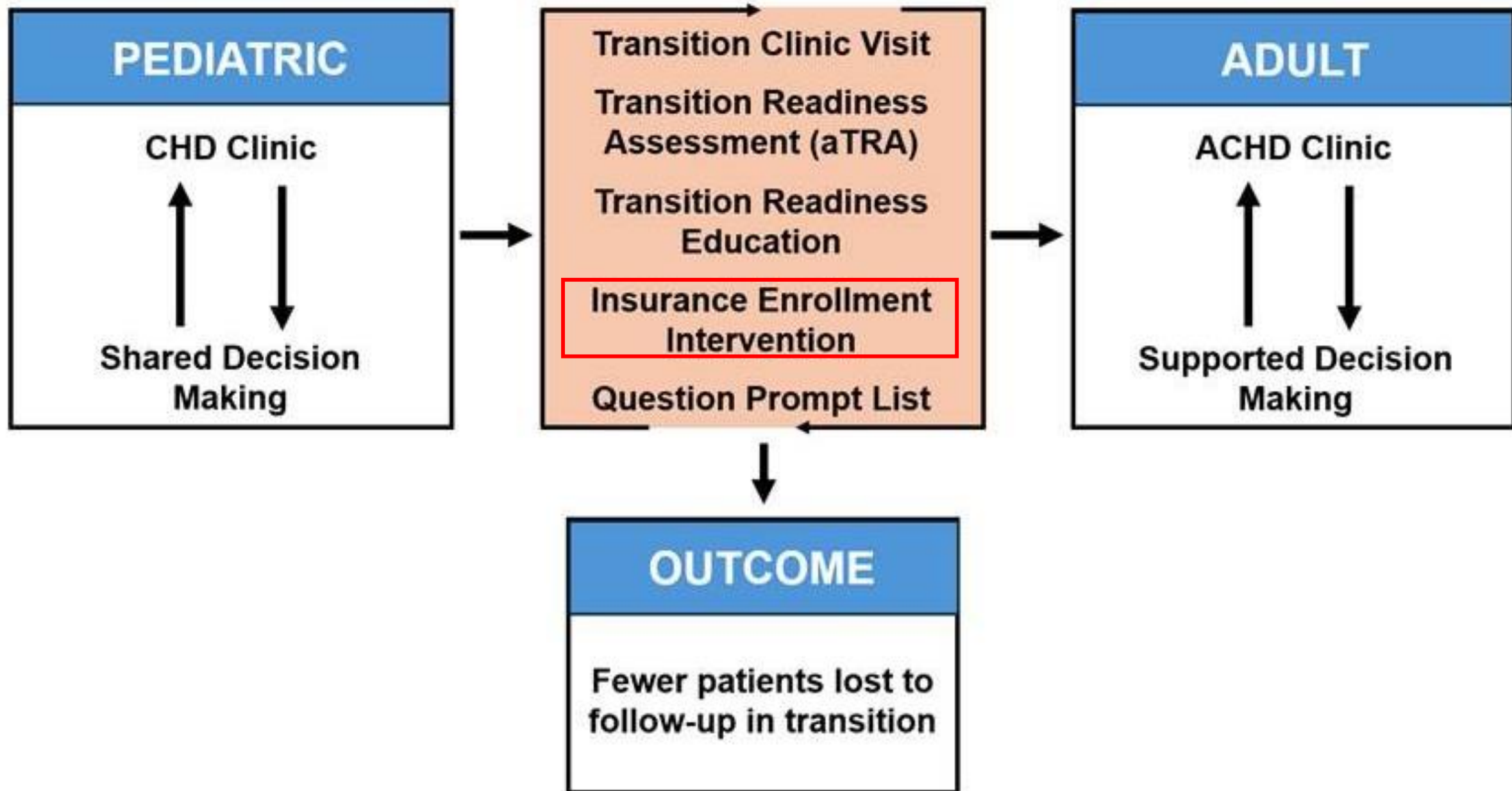
We do it, own it, feel it completely on our own. Isolation compounds the physical and emotional work.” *Ageing mother to a medically complex young person*





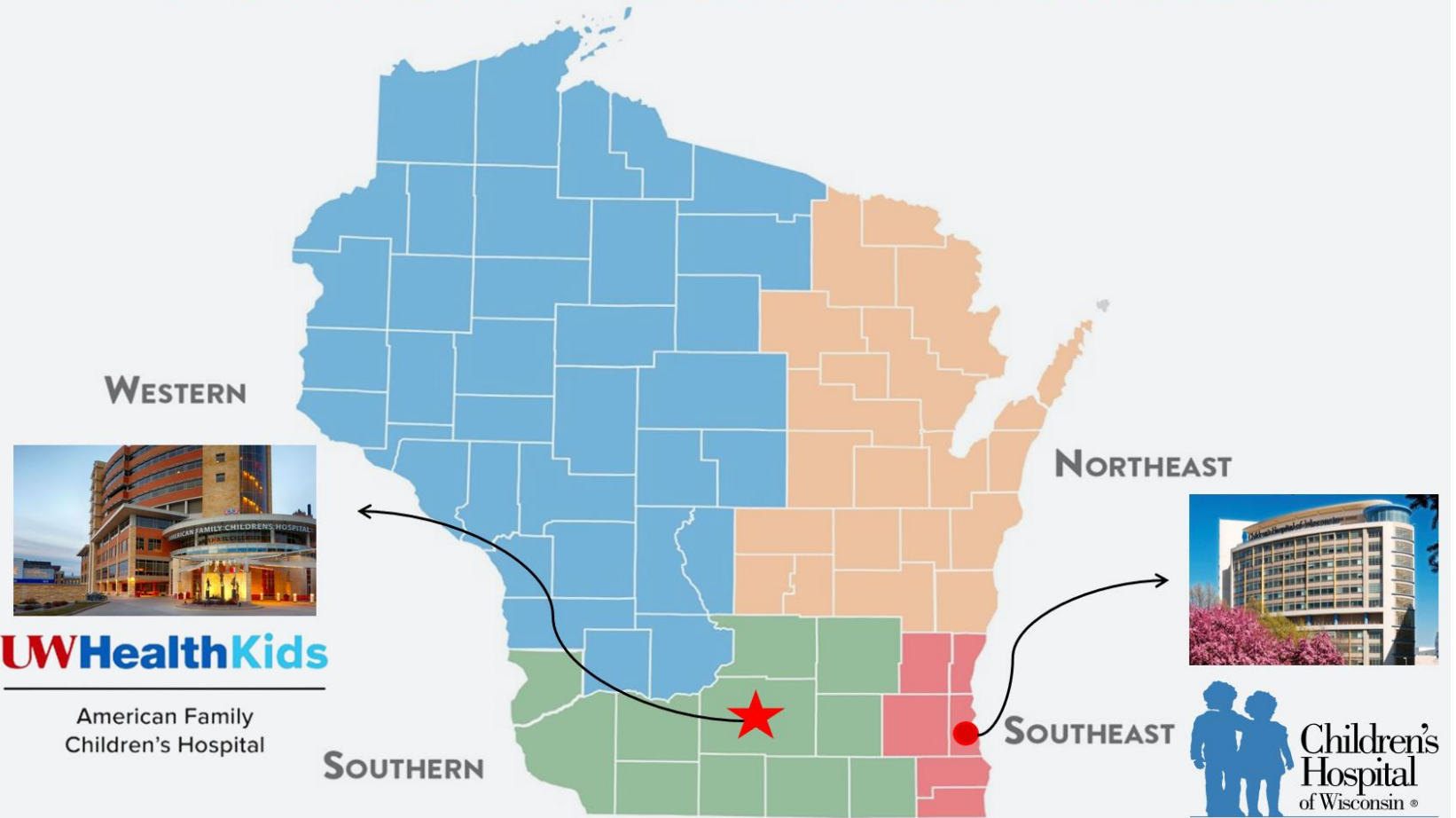






# Forward Pediatric Alliance

Preparing for a pilot in the two Wisconsin clinics covering all congenital heart disease patients statewide







Wisconsin Board for People with Developmental Disabilities



Adult Congenital Heart Association

The logo for the Adult Congenital Heart Association consists of two stylized human figures in red, one above the other, with a red checkmark below them.

covering Wisconsin



Wisconsin AAC Network



Lipoprotein(a) or Familial Hypercholesterolemia



Conquering CHD



Communication **FIRST**

Because communication is a human right.

HEART – WISE



Department of Workforce Development

Vocational Rehabilitation

**UWHealthKids**

American Family Children's Hospital



Children's Hospital of Wisconsin



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Social solutions for child health

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ACHA  
Youth Health Transition Initiative  
Communication First  
Survivorship Advisory Board

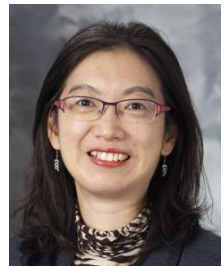
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<https://go.wisc.edu/6yza74>



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# Upcoming Event



## YHTI Learning Community

Lessons from the Field: Health Integration with Special Olympics Wisconsin

September 25, 2025

12:00pm-1:00pm

More information and to register:

<https://healthtransitionwi.org/health-transition-learning-community/>

Future topic/date:

Nov 20, 2025 - Healthcare Transition for Pediatric Patients with Diabetes: Getting READDY at School

Upcoming Event



# Health Care Transition for I/DD ECHO

Mental Health Barriers and Options during the Transition to Adult Services

May 13, 2025

12:00pm-1:30pm

More information and to register:

<https://www.waisman.wisc.edu/echo/health-care-transition/>

Future topics and dates

- Health Care Transition Services for those with Medical Complexity (6/10/2025)

# Upcoming Event



Thank you to the Mount Horeb Area School District Transition team for their partnership in the Spring 2025 edition of Transition Talks Tuesdays.

- Housing Options (March 4, 6:00-7:00pm)
- Guardianship and Supported Decision Making (March 18, 6:00-7:00pm)
- Aging and Disability Resource Centers (ADRC) (April 8, 6:00-7:00pm)
  - Health Care Transition (April 22, 6:00-7:00pm)
- Division of Vocational Rehabilitation (DVR) (May 6, 6:00-7:00pm)
  - Transportation Options (May 20, 6:00-7:00pm)

More information and registration at

<https://healthtransitionwi.org/transition-talks-tuesdays-spring-2025/>



# We need your feedback to improve!

- Please answer our brief poll questions before you go...