

Beyond Survival: Thriving with CHD

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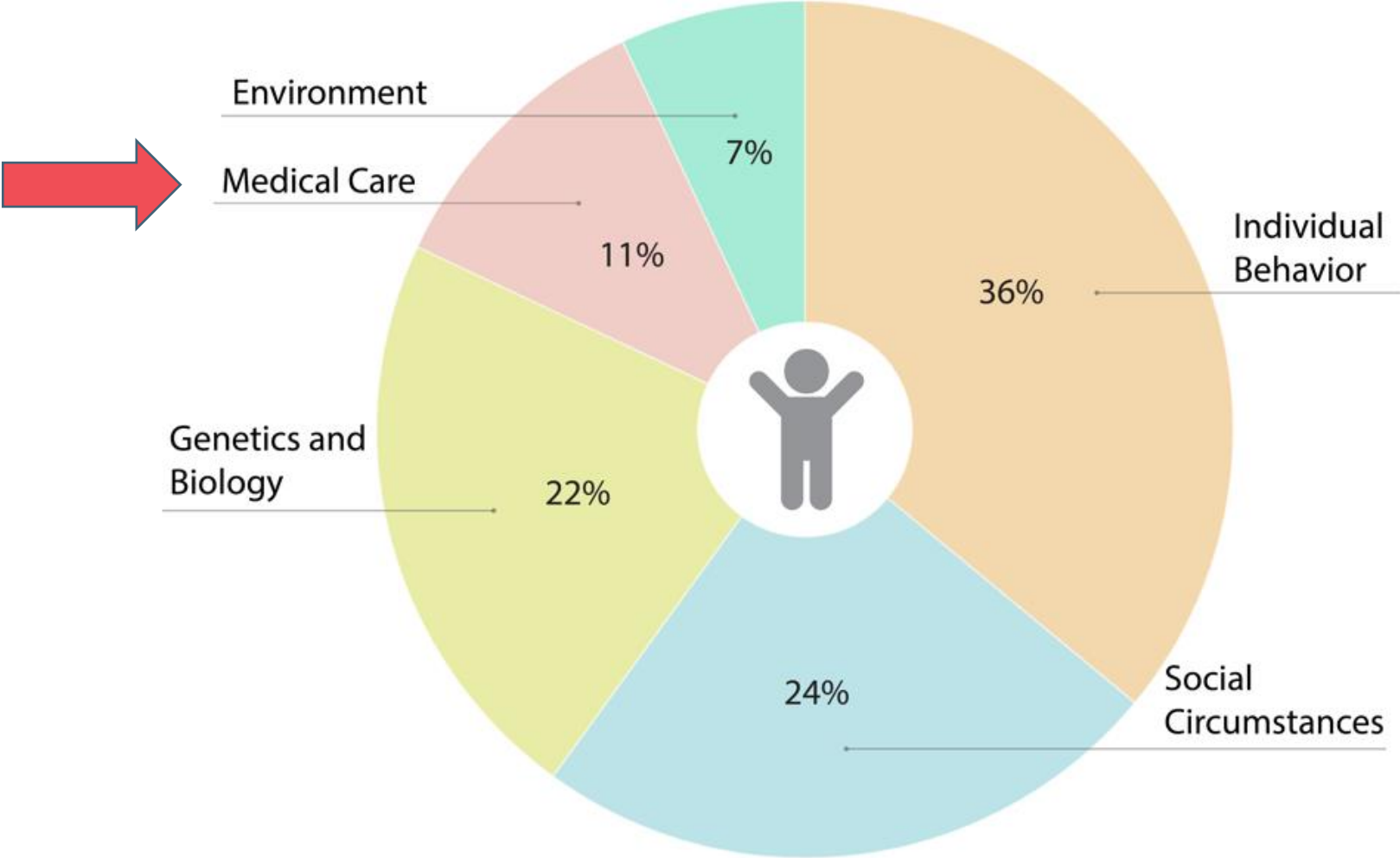


Presentation Outline

- **Background & Care Journeys**
- **Beyond the Medical**
 - **♥courage**
 - Understand
 - Journey Maps
 - Gaps in Care
 - Outcomes that Matter Most
 - Areas of Opportunity
- **Q&A/Comments**
 - Chat use

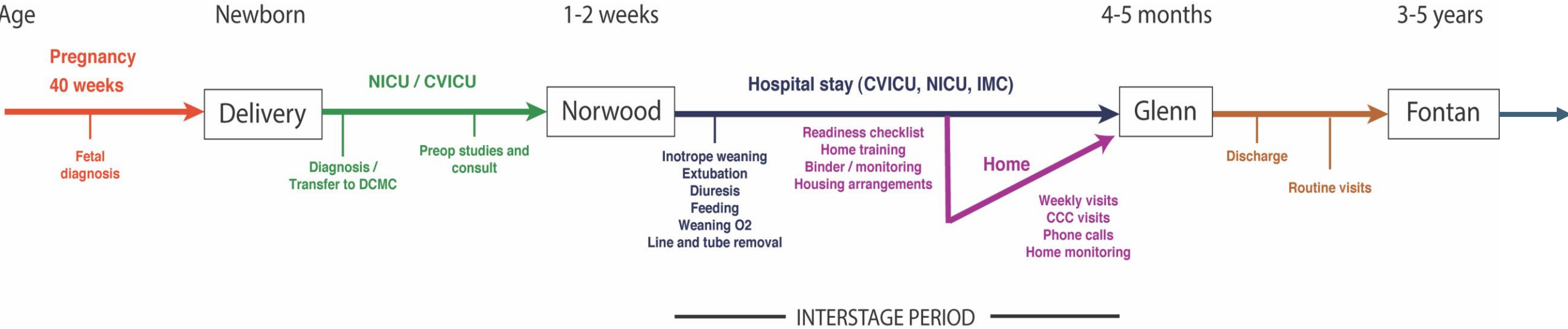


Care Journey: Current State



Modified from determinantsofhealth.org

Care Journey: Provider Perspective



Care Journey: Developmental Focus



How Do We Improve Care Beyond the Medical?



Claire (Courtney's daughter), age 9

corage

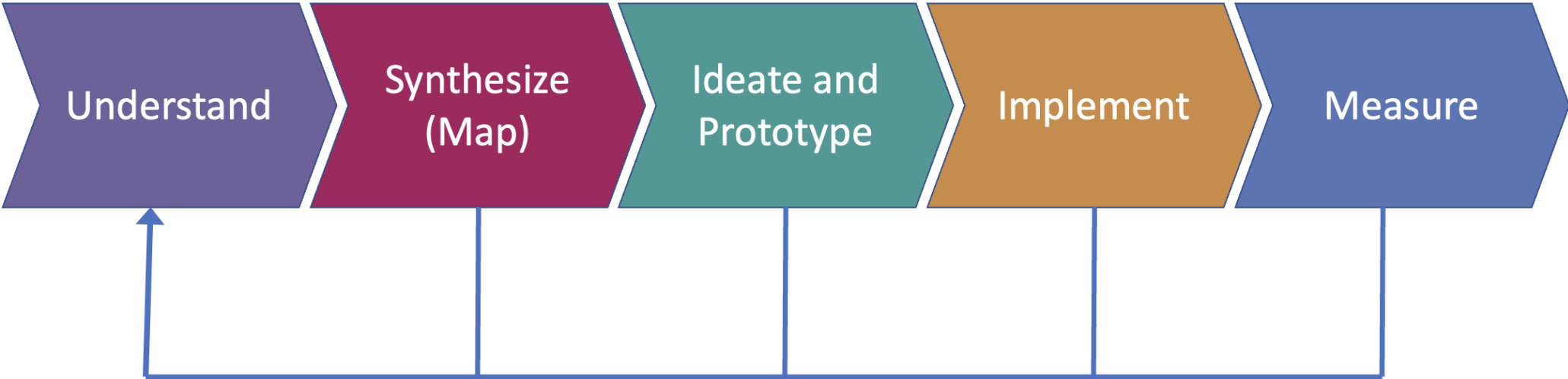
- To **map** and **redesign** the lifetime care journey of **individuals with single-ventricle heart disease and their families** to transform care in a more holistic and patient- and family-centered way that **maximizes their potential to have a fulfilling life.**

corage

- Visual mapping helps not only improve understanding of the journey and decrease uncertainty but also helps guide the development of health care redesign opportunities
- Health care transformation requires a multidisciplinary approach that starts by understanding the needs of patients and families

Understand

Understand: Patients and Families are Experts in Their Lived Experience



Understand: Experience Group Sessions and In-Depth Interviews



Understand: Participant Groups

• Patients

- Experience groups: 8 years and older
- Contextual interviews: 6 years and older

• Parents

- Parents with a fetal diagnosis
- Siblings 8 years and older
- Partners of adult patients
- Health care providers

1

Experience Group sessions

Written notes, audio recording

2

Moderator Debrief

Immediately after each session
(30-60 minutes)
Major themes begin to emerge

3

Transcription of all sessions

4

Research memo

2-page written brief
Summarizes key themes, questions, problems

5

First-cycle coding (NVivo)

Develop codebook with value, evaluative, and emotion coding of transcript data

6

Comparative coding memo

Moderators compare and combine codebooks
Refine/synthesize codes

7

Second-cycle coding

Refining and categorizing codes across multiple transcripts

8

Report of major themes

- Unmet needs
- Goals of care / most relevant outcomes
- Population segments



Understand: Participant Makeup

English-speaking



Spanish-speaking



10
Child patients

2
Child siblings

6
Adolescent patients

4
Adolescent siblings

29
Adult patients

12
Adult siblings

42
Parents of
child patient

4
Pregnant parents
w/ fetal diagnosis

8
Parents of
adolescent patient

17
Parents of
adult patient

6
Significant others

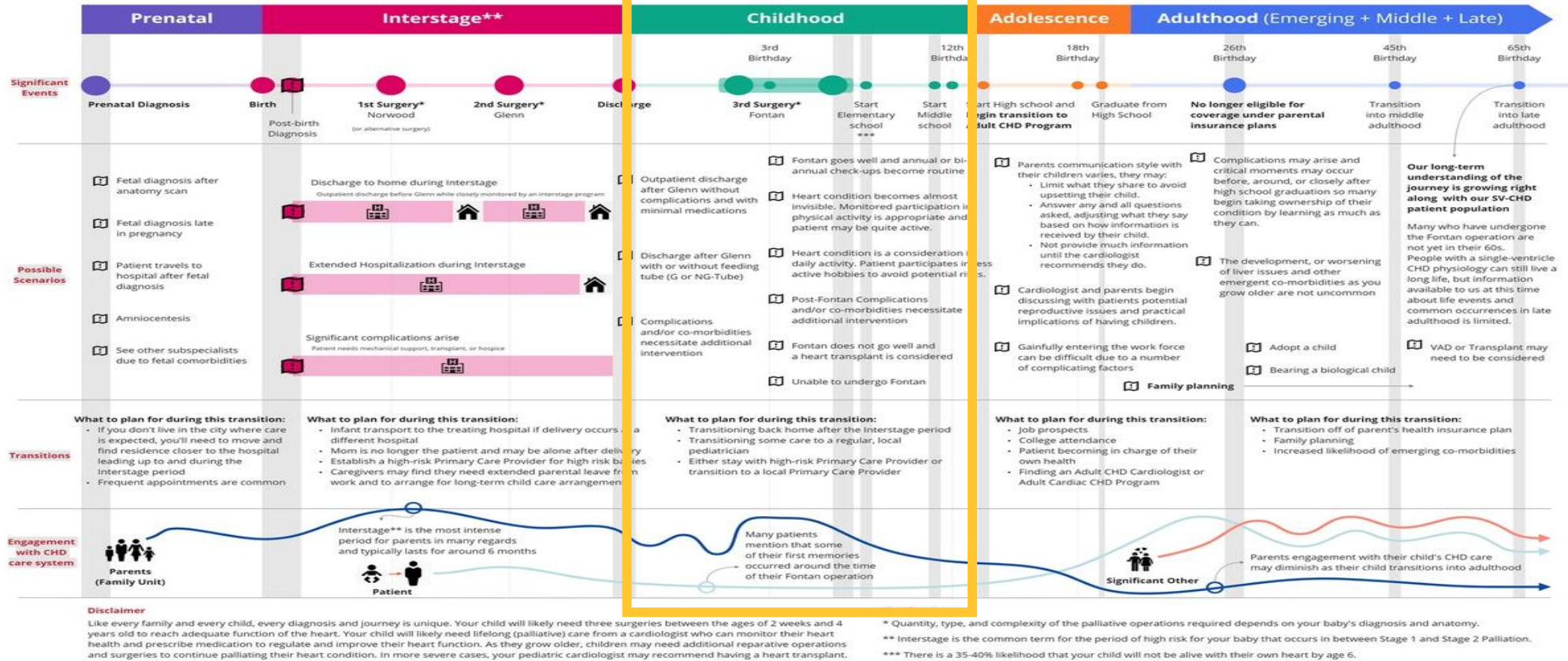
Journey Maps

Journey Maps: Overview



Lifelong Journey Overview: Single Ventricle Congenital Heart Disease

This map is meant to serve as a baseline overview of what you might experience throughout your life if you or your child are diagnosed with a Single Ventricle (SV) Physiology. Please understand that every person and their family have a highly variable life experience based on their diagnosis and living situation. More information is available online at: coragemap.com/



Journey Maps: Childhood Journey Map

- Significant Events
- Doing
- Thinking
- Feeling
- Pain Points
- Possible Scenarios



Journey Map
Homepage



Childhood
Journey Map

<https://coragemap.com/journey>



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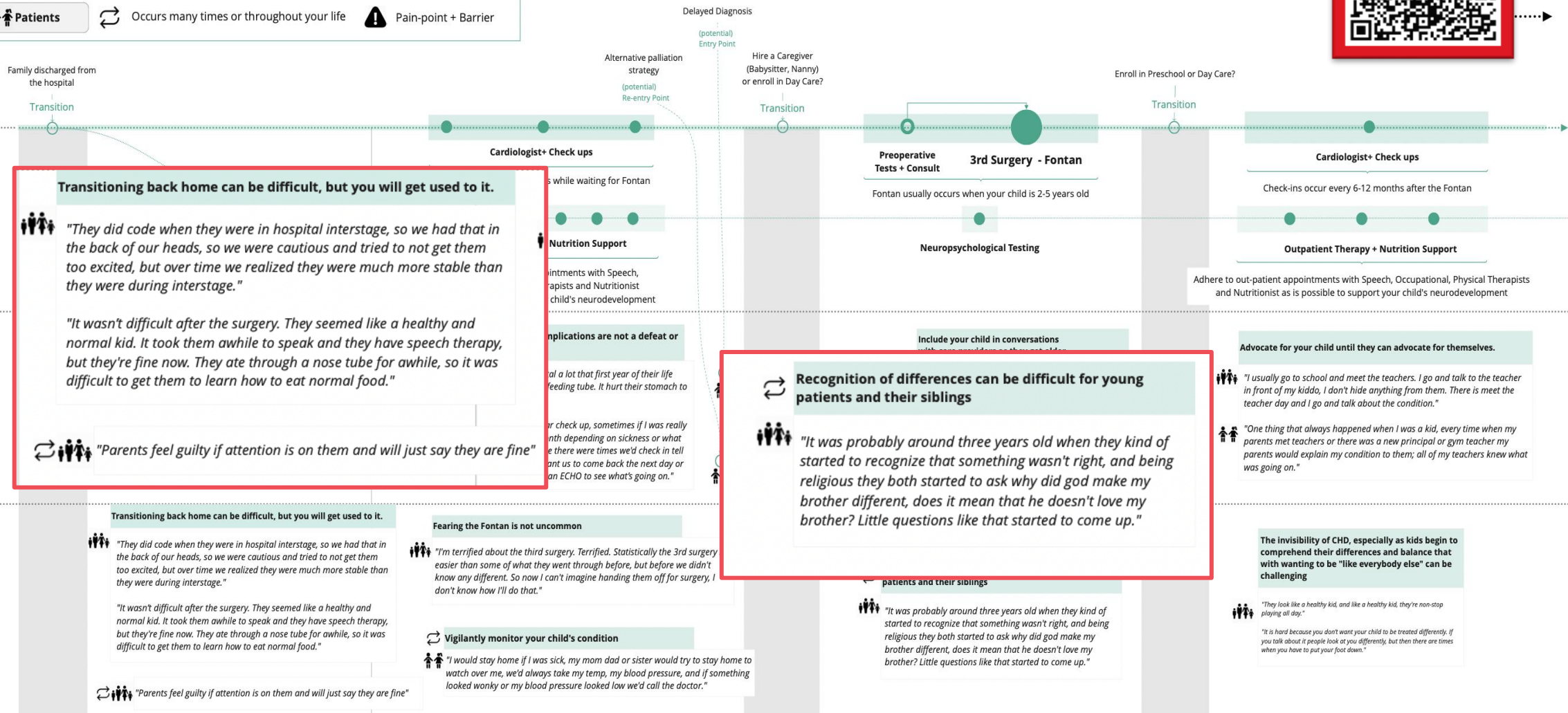


Journey Maps: Glenn to Fontan Examples



Childhood: Coming to terms with your condition as you grow up and start school.

Parents
 Patients
 ↻ Occurs many times or throughout your life
 ⚠ Pain-point + Barrier



Significant Events

Doing

Thinking

What actions are people taking to meet their needs?

What are their key behaviors?

How do people frame and evaluate their experience?

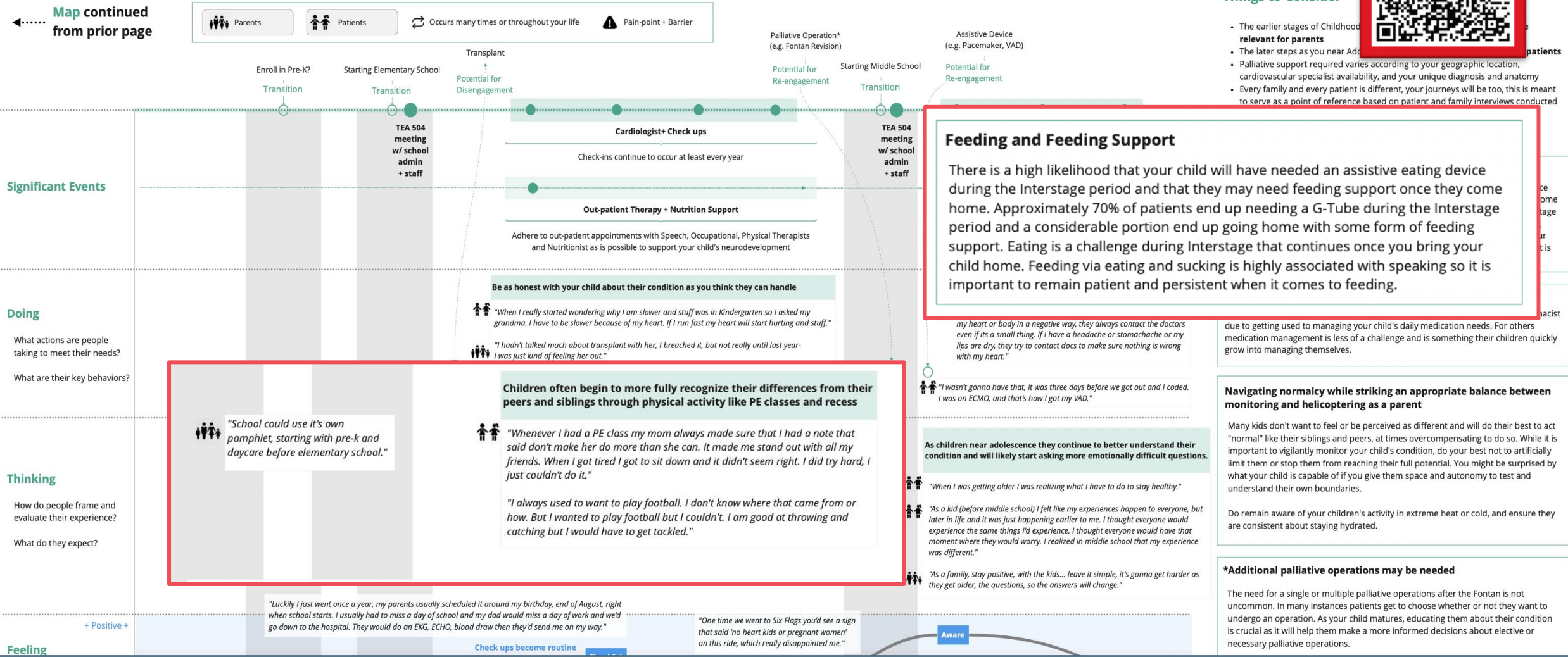
What do they expect?

Journey Maps: Glenn to Fontan Examples

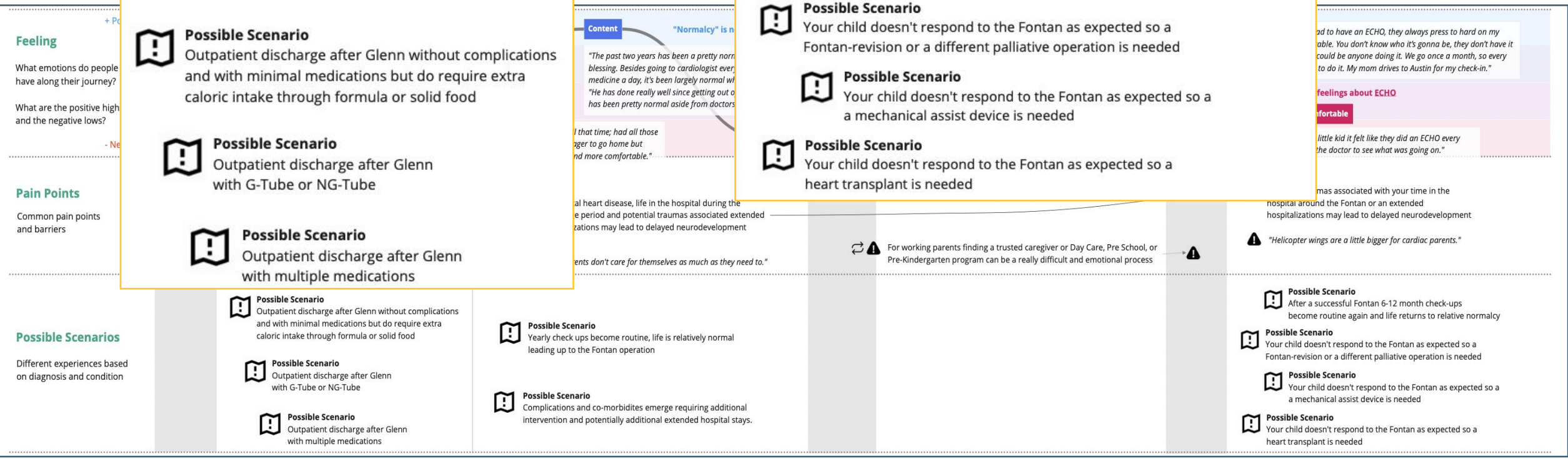


Childhood: Coming to terms with your condition as you grow up and start school.

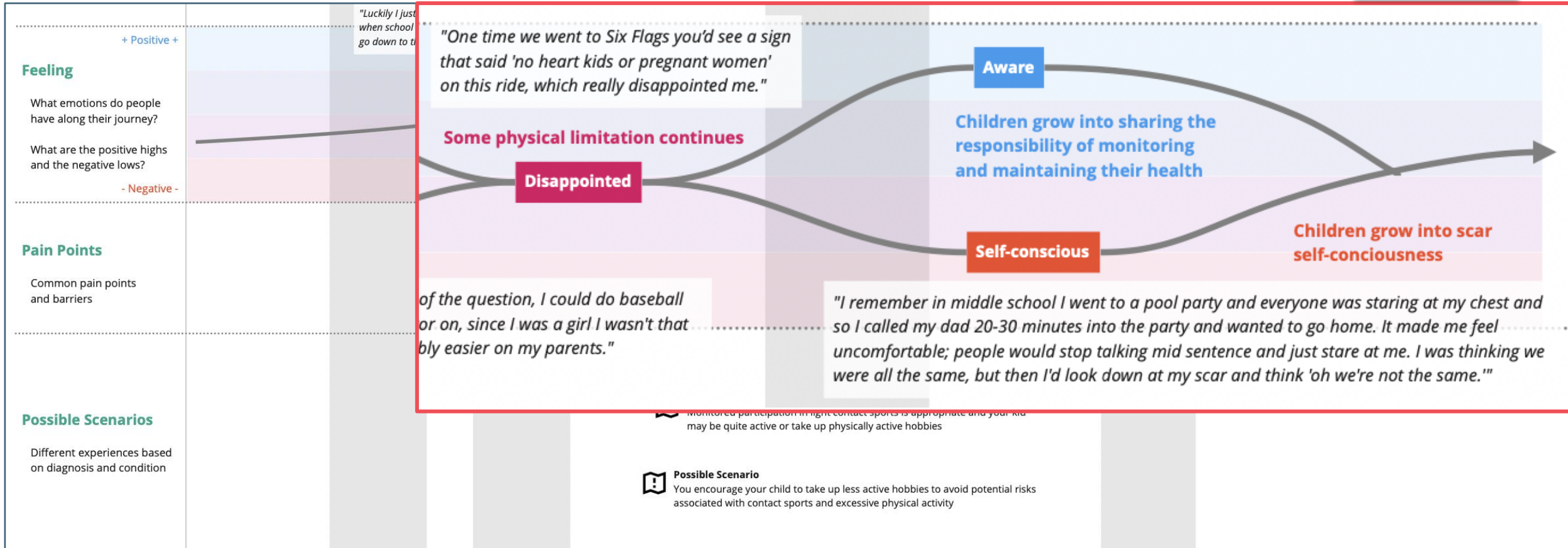
Map continued from prior page



Journey Maps: Glenn to Fontan Examples



Journey Maps: Glenn to Fontan Examples



Gaps in Care

Mentimeter



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What Gaps In Care Have You and Your Child Experienced in your Family's CHD Journey?



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Gaps in Care: Identified Gaps

Gap	Prenatal	Interstage	Childhood	Adolescent	Adulthood
Parents experience long wait times to see a CHD expert	●				
Access to affordable health insurance is a major barrier for many patients and families	●	●	●	●	●
Parents and patients often struggle with financial burden due to the condition	●	●	●	●	●
Rescheduling of surgeries is emotionally draining and logistically challenging for parents	●	●	●	●	●
Providers in other medical specialties frequently have limited CHD knowledge	●	●	●	●	●
Parents are the ones responsible for synthesizing and communicating critical medical information for themselves and to their providers	●	●	●	●	●
There are relatively few providers who specialize in adult CHD care				●	●

- Communication
- Transitions across life stages
- Patient and family support
- Structural deficiencies in care
- Education



Gaps in Care: Common Themes

- Uncertainty in the journey
- Significant stress, anxiety, guilt, and emotional distress
- Difficulties during the different transitions in life
- Need to connect with peers and other affected families
- Need to maintain a sense of normalcy
- Family planning and romantic relationships
- Value of resiliency and adaptation

Outcomes that Matter Most

Outcomes that Matter Most: Parents

- Maintaining a sense of hope
- Connection with other parents
- Support through the emotional fatigue
- Navigating the change in role as child transitions between life stages
- Consistent accessible information about goals and expectations



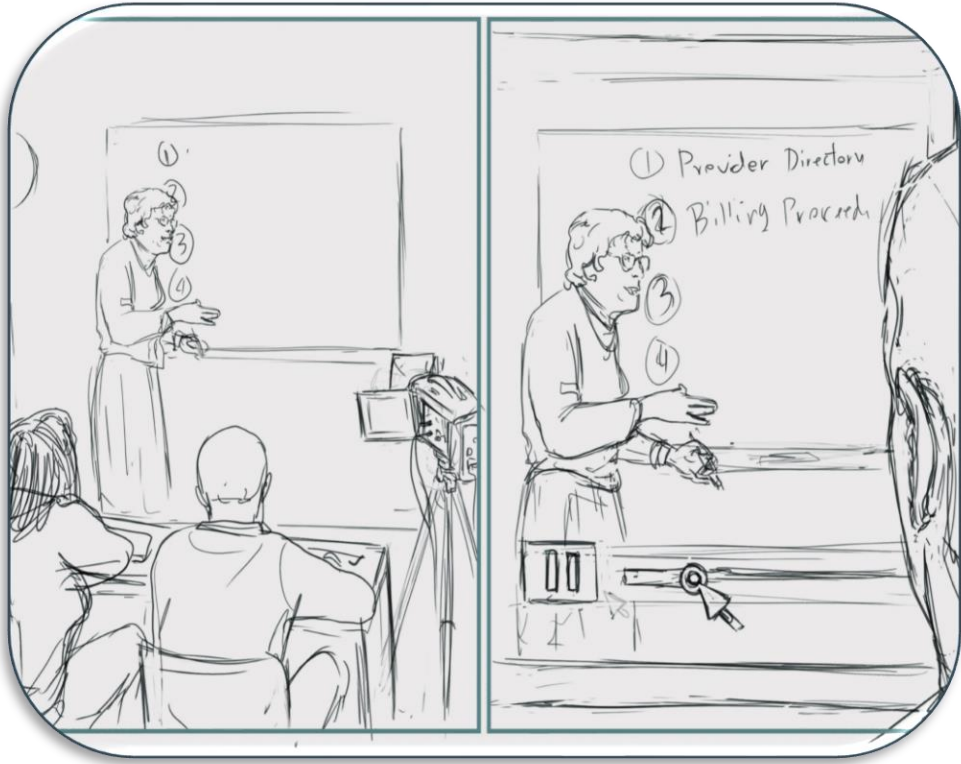
Outcomes that Matter Most: Patients

- Condition-specific proficiency and compassion in emergency room care
- Reducing the financial cost burden of care
- Smoother transition into adulthood
- Connection with other people living with the condition
- Learning ways to cope with uncertainty and fear



Areas of Opportunity

Areas of Opportunity: Health Network Navigation



Rationale:

Insurance is always mentioned as one of the main sources of stress. Even otherwise knowledgeable people had a difficult time understanding insurance and knowing their rights. Similar to commercially insured people, Medicaid recipients do not know what the program covers and what it doesn't, in all likelihood some providers are probably similarly unsure.

Description:

A course-series (to be recorded, live-streamed, and shared online for posterity and promotion) to teach parents about the complexity of insurance, how hospitals work, and other technical information since they will be heavily involved with the provider network and the health systems. Educate people about what Medicaid already covers and other low-cost options for insurance. Work with an external organization for that. To afford consistent engagement with a single person w/in Dell Children's, who - similarly to an insurance agent, primary care doctor or broker - will be their advocate in the organization, a new role for the instructor(s) of this educational series will need to be created and staffed. This role will be a blend of the roles and responsibilities of Social Workers, Nurse Navigators, and Financial Support.

Areas of Opportunity: Designated Patient Advocates



Rationale:

A common desire for a "quarterback" or a single clinical point of contact to guide parents through the clinical system, especially during the Interstage period was shared. There are currently Nurse Navigators available to support patients and families and/or to coordinate internal efforts during the Interstage period. Other programs employ providers focused solely on communicating with patients and families.

Description:

This opportunity calls for an expansion of the Nurse Navigator role that focuses more on communication and coordination support. Designate a Nurse Navigator to each family, Surgeon, or Cardiologist leading up to, during and near-term beyond the Interstage period. This can be approached in a way that is similar to how the Comprehensive Care Clinic designated a single nurse to each of their complex child patients. This is a step towards a health system that does not require internal advocacy, and promotes efficient and seamless communications between all parties involved.

Areas of Opportunity: CHD Brothers & Sisters



Rationale:

Many CHD patients have not met others their age living with SV-CHD. Some SV-CHD patients have never met anyone else with CHD much less SV-CHD. Most everyone we spoke to was enthusiastic about the idea of a Big Brothers Big Sisters style peer mentorship program. Older "zipper brothers and sisters" can act as role models for younger patients, while younger patients can be inspired by them. This relationship offers value for both the older peer mentors and for the younger patients being mentored.

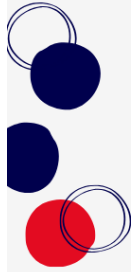
Description:

A volunteer-supported mentoring network, like the Big Brothers Big Sisters Community-based Mentoring Program. Promote meaningful, monitored matches between adult volunteers ("Bigs") and children with CHD ("Littles"), ages 5 through young adulthood. The aim is to develop positive relationships that have a direct and lasting effect on the lives of young people.



If you or your family member are going through the
diagnosis of

Single-Ventricle Congenital Heart Disease



we invite you to take 10 minutes to answer this survey on unmet health-care needs
so we can start closing the gap



#letsclosetheCHDgap



This survey will be used for research purposes
If you have any questions about this research, you may contact us at cardiacresearch@austin.utexas.edu



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Areas of Opportunity: Where Do You See Opportunity?

As NPCQIC and FON come together to consider the lifetime journey for CHD patients and families, what gaps in care and opportunities do you think we should focus on?



Get Involved: Share your ideas for the Post Glenn to Fontan Surgery at info@npcqic.org



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Questions
and
Comments
Welcomed!