



Delaware's Commitment to Understanding Caring for Children with Medical Complexity

Home and Community-Based Services Conference
December 2020

TODAY'S AGENDA

1. STEERING COMMITTEE FORMATION
2. ADVISORY COMMITTEE MANAGEMENT
3. FAMILY SATISFACTION SURVEY
4. QUESTIONS + DISCUSSION

1. STEERING COMMITTEE FORMATION

CHILDREN WITH MEDICALLY COMPLEX NEEDS

- A small and quickly growing population in Delaware
- Can be affected with rarest, most severe, functionally limiting, and life-threatening health problems
- Impact on the health care system



LEGISLATIVE ACTION

- House Substitute No. 1 for House Bill No. 275
- Budget Epilogue Section 141: Address the needs of Children with Medical Complexity (CMC)
- Comprehensive Plan for CMC
- Public Process



STEERING COMMITTEE FORMATION

- Community Partners
- Sister Divisions
- Parents
- Caregivers
- Community Advocates



ISSUES SURFACED BY FAMILIES

- Misalignment between health care landscape and children's needs
- Need for a definition
- The journey we took together...
 - Formation of a steering committee
 - Subcommittees and workgroups
 - Steering Committee recommendations



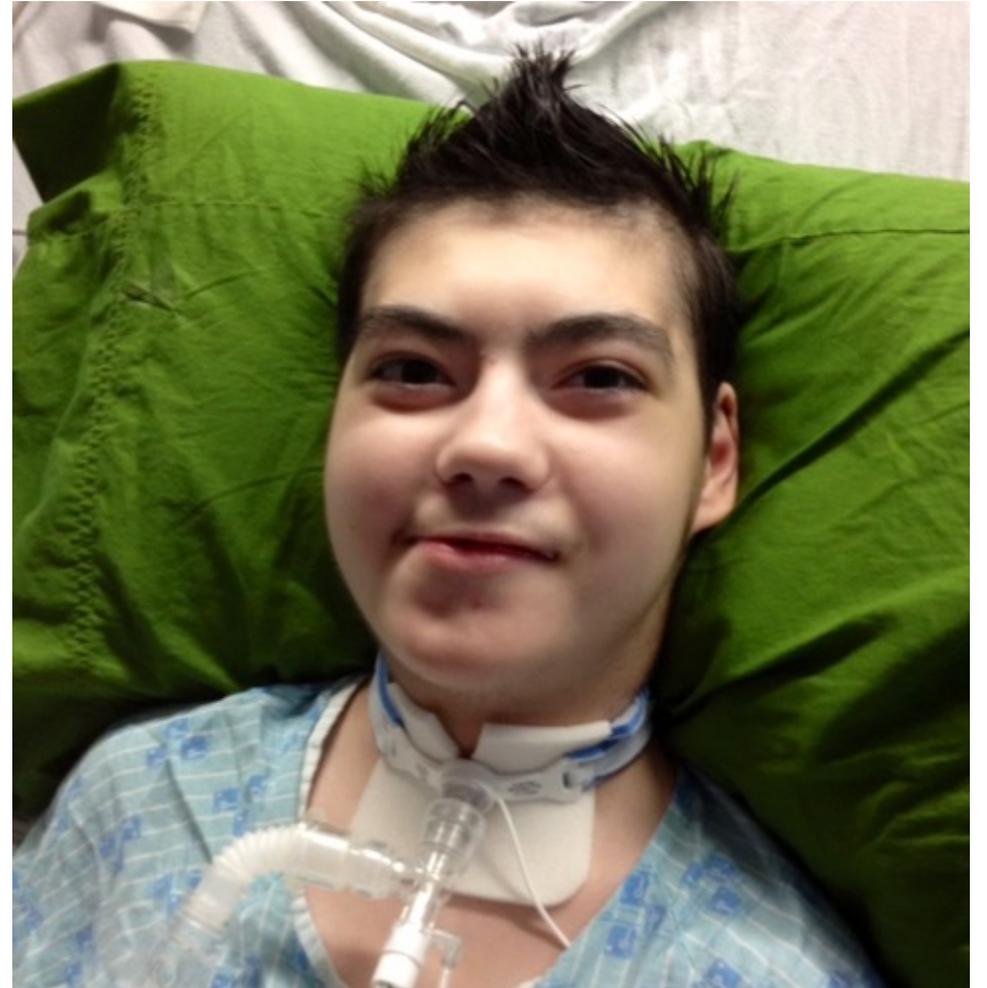
DEFINING CHILDREN WITH MEDICAL COMPLEXITY

- 1 or more chronic health condition(s) with significant morbidity or mortality;
- Functional limitations impacting Activities of Daily Living (ADLs);

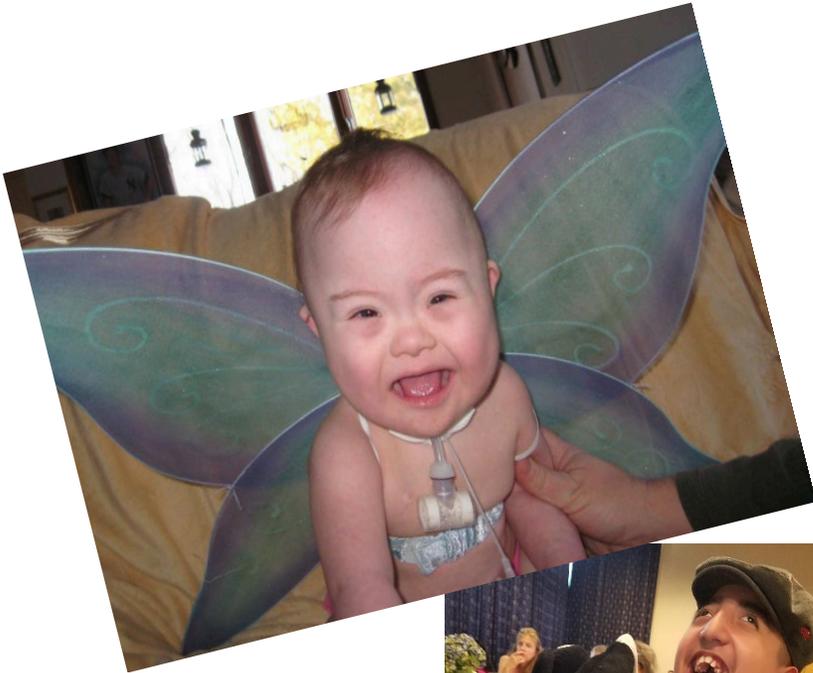
- High health care needs or utilization patterns;
- Dependence on technology.

STEERING COMMITTEE WORKGROUPS

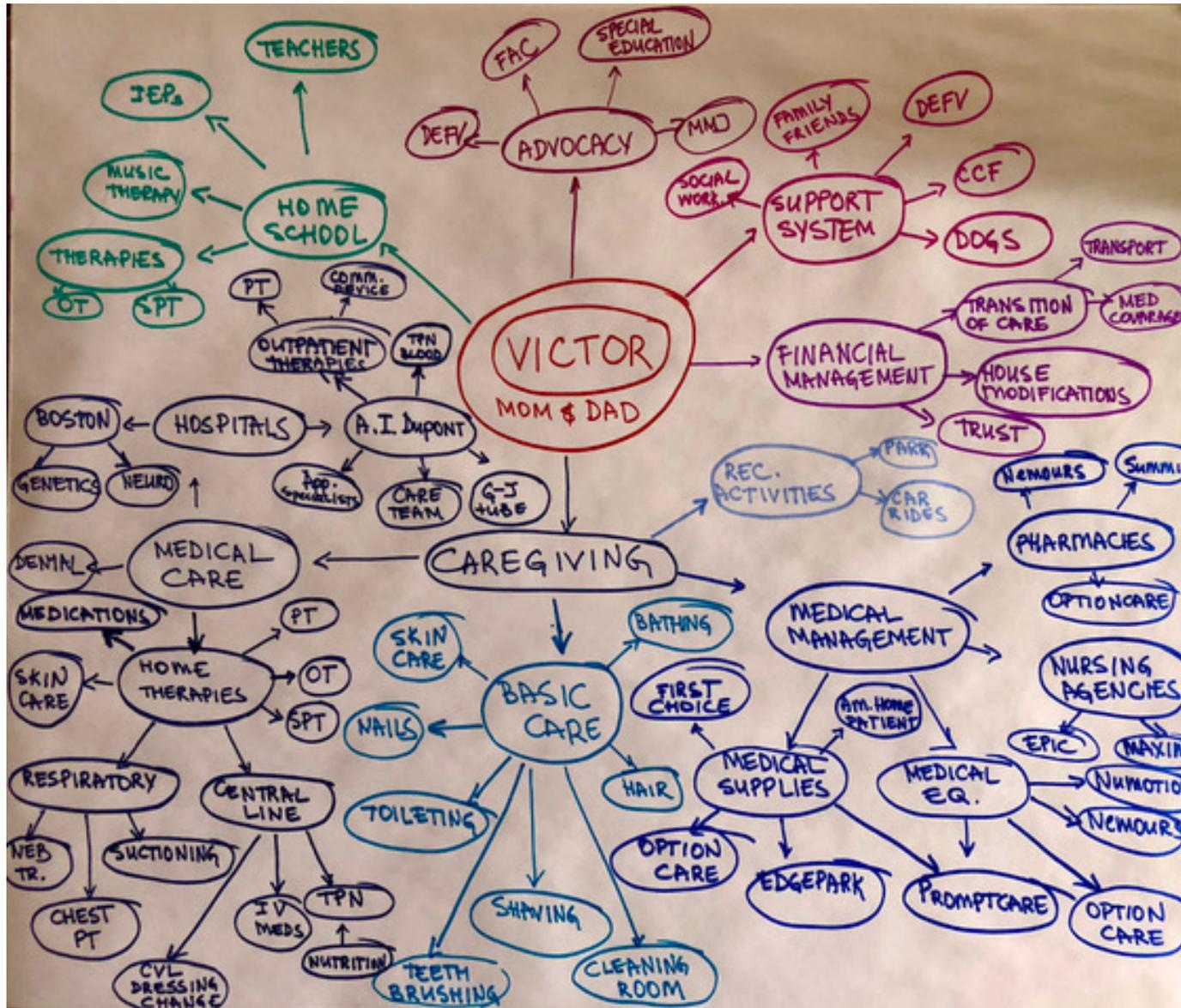
- Data
- Payers
- Models of Care
- Access



COMPLEX AND UNIQUE



MEDICAL COMPLEXITY: GAPS + CHALLENGES



- Care Coordination
- Provider Capacity
- Durable Medical Equipment and Supplies
- Pharmacy
- Transportation
- Nursing and other Supportive Services
- Transition to the Adult System of Care

RECOMMENDATIONS + NEXT STEPS

- Strengthen the network of home health providers
- Strengthen systems of care
- Develop/strengthen existing resources
- Perform a comprehensive data analysis
- Keep Steering Committee in place

2. ADVISORY COMMITTEE MANAGEMENT

NATIONAL PERSPECTIVE

- 3% of children in the United States, yet health care spending for the group makes up an ~40% of spending for children's health care under Medicaid
- High-risk for emergency department visits and hospitalizations.
- Health care systems are facing growing challenges around capacity management and patient access.

MERCER'S ROLE IN SUPPORTING DELAWARE

Policy support

- Guidance on clinical practices around providing support to children
- Review of policies and regulations such skilled home health agency licensure regulations
- Private duty nursing authorization process
- HCBS medically complex programs

Provide national perspective on issues

- Family centered cultural competency training
- Respite programs

MERCER'S ROLE IN SUPPORTING DELAWARE

Assistance in stakeholder engagement

- Facilitating workgroup meetings
- Developing and management work plans

Data analysis support

- Analysis of MCO Gaps in Care data reports
- Modifying CMC survey list

ADDITIONAL SUPPORT

Bridging the gaps

- Stakeholders
- DMMA

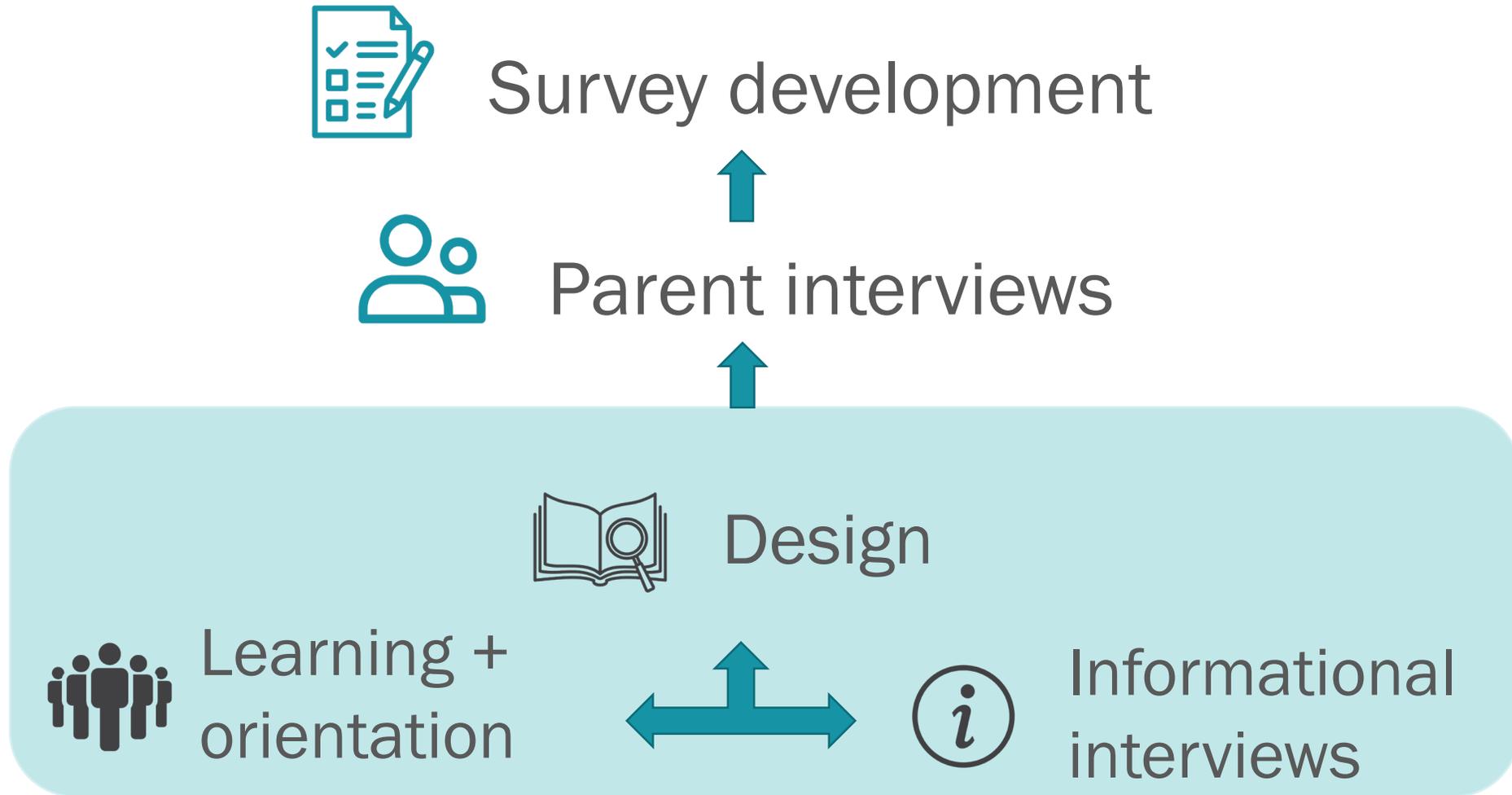
Bringing appropriate supports to the project

- Clinical support
- Data analysts
- Research experts



3. FAMILY SATISFACTION SURVEY

PROJECT OVERVIEW



PARENT INTERVIEWS: DESIGN



Families randomly sampled

3

Sub-groups of interest

\$

Gift card incentives provided



Phone interviews

PARENT INTERVIEW PROTOCOL

- Families' stories
- Success + Challenges
- Access + quality of services
- Care coordination
- Primary + specialty medical care
- Home health nurses + aides
- Insurance
- Gaps in services

11 PARENT INTERVIEW PARTICIPANTS

10

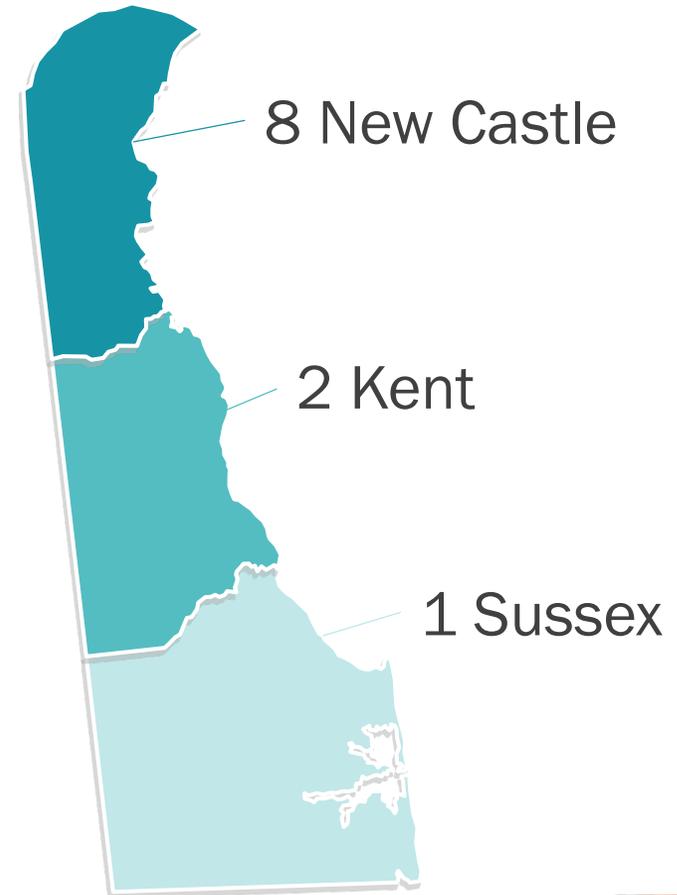
Mothers

2

Spanish speakers

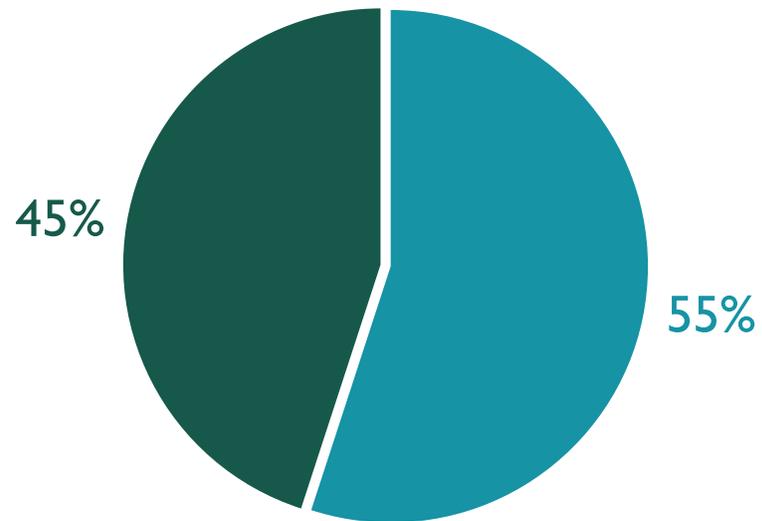
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Counties
represented

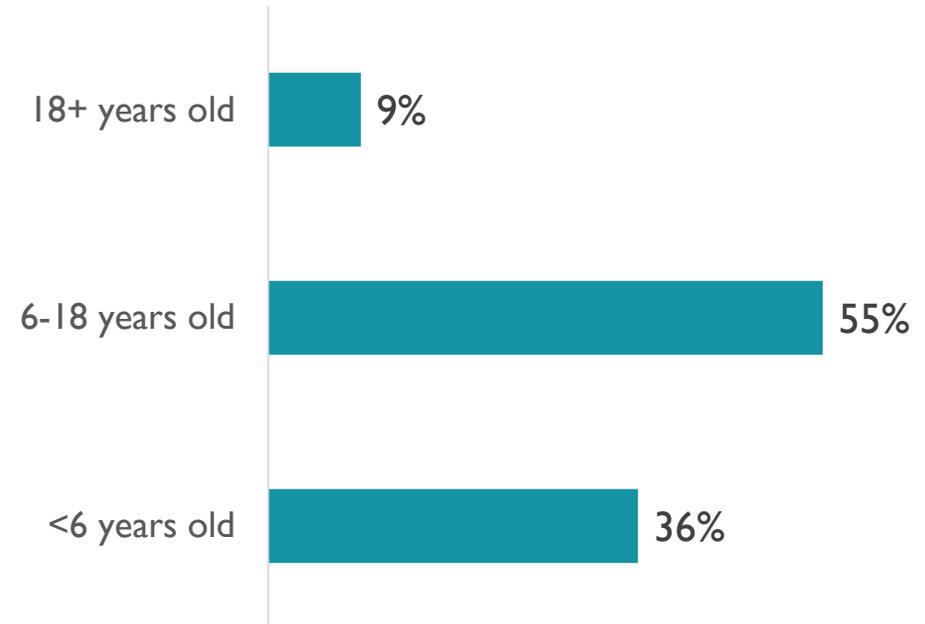


CHILD CHARACTERISTICS: INTERVIEW PARTICIPANTS

Almost even numbers of **female** and **male** children represented.

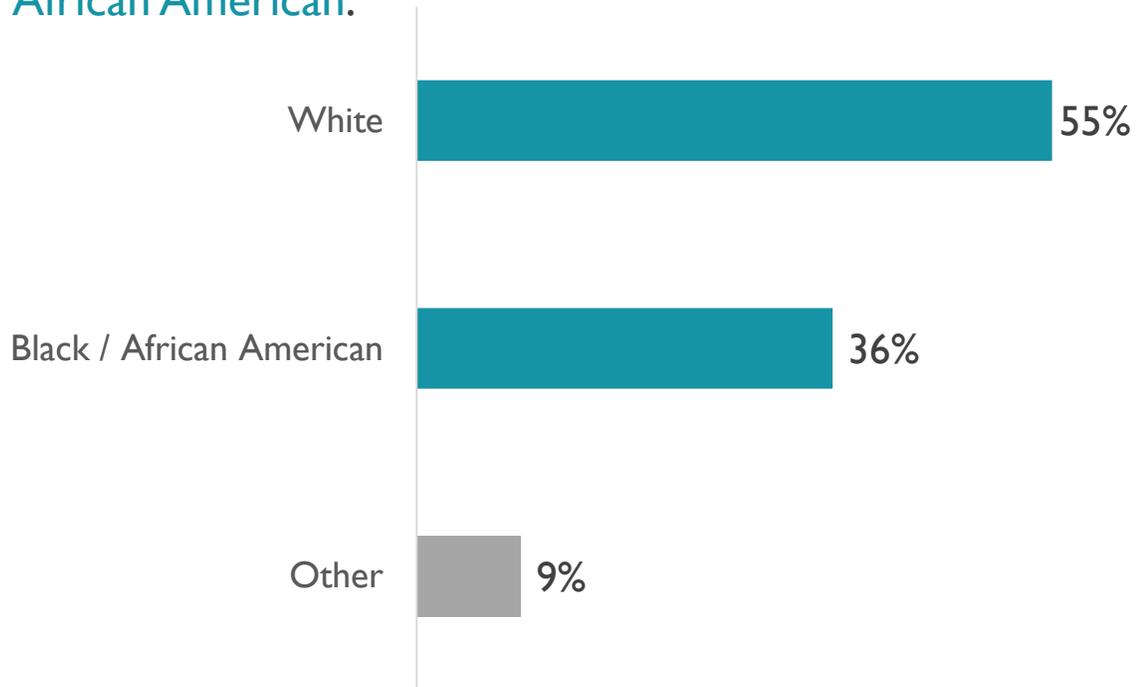


Child ages varied but most were **6-18 years old**.



CHILD CHARACTERISTICS: INTERVIEW PARTICIPANTS

Children represented were mostly **White** or **Black / African American**.



Children's **disabilities** and **diagnoses** varied substantially.

PARENT INTERVIEWS: UNIQUE AND VARIED STORIES

Supports

- Parent SES
- Ability to advocate
- Individuals working within the system

Challenges

- Transitions
 - Care providers
 - From pediatrics
- Language
- Medicaid application/eligibility processes
- COVID-19: differential impacts

SURVEY DEVELOPMENT



NEXT STEPS: SURVEY ADMINISTRATION



Mail surveys to full sample



On-line completion option



SURVEY RESULTS – LOOKING AHEAD

- The CMC Advisory Committee & DMMA launched a private duty nursing workforce study
- Results from both studies will provide the CMC Advisory Committee and DMMA deeper insight into the challenges families face
- Results will be used to develop strategies to address areas of most concern to families through:
 - Advocacy
 - Research
 - Policy
 - Operational revisions

4. QUESTIONS + DISCUSSION

THANK YOU!

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