Washington State Department of HEALTH

Family Advisory Council 2023 Report

Introduction

Children and Youth with Special Health Care Needs (CYSHCN) and their families often need extra support to stay healthy and thrive. The Washington State Department of Health's (DOH) Children and Youth with Special Health Care Needs Program is committed to involving families and youth from the very start to create programs that make a meaningful impact for families.

We believe families are the primary experts on the child's needs. That's why care should center on the well-being of the child and family. Improving systems that serve CYSHCN takes strong leadership, persistence, and active partnership between families, state agencies, and other community partners.

The Family Advisory Council

In 2023, Washington launched the Family Advisory Council (FAC) as part of the state's participation in Project ACCELERATE. This project brought together Maternal and Child Health (Title V) programs, Medicaid agencies, and family leaders to improve care coordination policy for CYSHCN.

Although family leaders and family-led organizations were already involved in Project ACCELERATE, the FAC was created to expand opportunities for families with a wider variety of experiences to give input and help shape systems and policies.

The long-term vision is to develop a robust group of family leaders who continue to advise DOH and other state agencies working to improve the system of services for CYSHCN.

Health care providers can check for allergic antibodies using skin prick testing or serum IgE testing. Having these antibodies doesn't always mean someone has a clinical allergy. A monitored oral food challenge can help pinpoint specific food allergies.

Recruitment Process

A subcommittee formed from the boarder Project ACCELERATE team in February 2023 to plan for and run the FAC. Their first step was creating an informational flyer to recruit members. The flyer offered information about:

- The purpose of FAC
- Meeting information (how often the group would meet and in what format)
- Member compensation

The flyer featured inclusive images, plain language, and a clickable link and QR code for accessibility. It was made available in English and Spanish and shared through listservs, social media, and partners, including family-led and family-serving organizations.

Special attention was given to better reach families of color and those living in rural areas of the state.

To make sure the FAC membership reflected a range of possible experiences unique to the CYSHCN population, applicants were asked about:

- NICU and specialist care.
- Birth-to-three or school age special education services.
- Types of health needs or disabilities.
- Socioeconomic status and insurance type.

FAC members were selected in June 2023.

Membership

FAC members are parents and caregivers of CYSHCN. Many are caregivers to children with multiple diagnoses or care for more than 1 child with special health care needs. The group is committed to building a membership that reflects the families of CYSHCN across Washington.

In its first year, FAC included **15 family members** from across the state, with different identities and lived experiences such as health care needs and insurance types. Members came from both rural and urban communities.

DOH and other state and local agency staff plan for and attend the FAC meetings in a limited role to prioritize the families in room. Many agency staff involved also have personal connections to this work—as caregivers or family members of people with special health care needs and disabilities.

Feedback We Have Received

Membership Participation

FAC members share a common goal to learn from each other and share their experiences as z

They value:

- Opportunities to exchange ideas about what works and what doesn’t.
- Knowing their feedback reaches staff from DOH and other agencies.
- Time for personal connection and peer support.

The members noted the emotional weight of caregiving and supporting other families. During meetings, they highlighted the need to balance advocacy with self-care to avoid burnout.

The FAC identified several ways to strengthen the group:

- Share information about the FAC through members' networks and schools to recruit new members.
- Use a communication channel like a discussion forum or email list to share updates and feedback between meetings.
- Provide structured meeting agendas, while allowing time for open discussion and connection.
- Invite agency staff to explain their roles and connection to the FAC.

All meetings were held virtually on Zoom. The members confirmed they had the technology needed to participate. Meetings were held monthly from July to September, with an additional meeting in December. Only 2 members were able to attend the August meeting due to a heat wave that caused power outages in rural areas on the western side of the state, To be inclusive to various needs during meetings:

- Cameras were not required.
- Members could contribute verbally or use chat.

Care Coordination

Throughout the first year, members shared valuable insights based on their experiences as parents and caregivers of CYSHCN. Their discussions highlighted key challenges, needs, and suggestions for improvement. The following emerging themes align with the Blueprint for Change for CYSHCN framework.

Quality of Life and Well-being

When a child needs extra care, the mental and physical health of parents and caregivers often take a backseat. Families need support that focuses on the future well-being of not just the child's needs but the whole family's.

Access to Services

Families often experience gaps in care or get lost between systems that don't work well together. FAC members said the systems that serve children and youth with special health care needs must be better connected.

Financing of services

Getting services paid for is often so hard that families avoid using available resources. The process is too confusing. Making it easier for families to get funding and be reimbursed for the care their children's need is essential.

Improving Health Outcomes for All

Families stressed how important it is to keep talking about disability and diversity. Services should be fair, inclusive and responsive to different cultures and backgrounds.

Quality of Life and Well-being

CYSHCN and their caregivers often feel more isolated and experience poorer mental health than their peers. While each person and family defines the quality of life and well-being differently, these concepts cover more than managing appointments and accessing services. Quality of life and well-being is about supporting the whole person and their entire family in their daily lives.

FAC members shared the following:

- Many family caregivers feel like they are project managers or care coordinators, with some describing themselves as caregivers before parents and that they are doing “advocacy all day, 24/7.”
- The entire family needs more mental health support.
- Health and wellness needs for family caregivers become a lower priority, which can lead to long-term health issues.

Access to Services

CYSHCN may receive a wide variety of needed services and support through different systems of care like health care, education, and the Developmental Disabilities Administration (DDA). But these systems don’t always work together which leads to fragmented care. Families often have to coordinate on their own or even coordinate the coordinators.

FAC members noted:

- Gaps between systems, like providers, resources, and care coordination.
- Provider shortages, especially for families in rural areas who must travel for care.
- Need for more culturally matched care with providers who reflect the communities that they serve.
- Medical providers who lack empathy.
- Lack of services and support for those who don‘t qualify for DDA.

Helpful resources mentioned:

- Parent to Parent (P2P)
- Providence Carousel Program
- Wonderland Child and Family Services
- DDA Case Resource Managers (CRMs)
- County health departments

Financing of Services

CYSHCN need more medical care, therapies, services, and supports than their peers--and these services can be costly. Even with insurance, families can experience barriers accessing services they qualify for, such as state reimbursements for medical travel and DDA grants on the Individual and Family Services (IFS) waiver.

FAC members described:

- Complicated processes which create barriers for families.

- Difficulty finding providers who accept Medicaid.
- Challenges with Medicaid insurance benefits and reimbursement.
- Challenges with private insurance benefits and reimbursement.
- Regulatory barriers that prevent access to out-of-state telehealth services.

Improving Health Outcomes for All

All CYSHCN have a fair opportunity to reach their optimal health and thrive throughout their life. CYSHCN come from all racial and ethnic groups, live in rural and urban areas, and have varying income levels.

1 in 4 children and youth (birth to 18) in Washington have special health care needs. They come from different backgrounds, neighborhoods, family structures, and have a range of medical conditions and disabilities.

FAC members shared:

- Personal experiences of being the only person of color in many CYSHCN spaces.
- Personal experiences of racism when accessing necessary services.
- Personal experiences of racism when interacting with the child welfare system.
- Avoiding activities not designed for CYSHCN, due to lack of accessibility for their child's social, communication, and health needs.
- A strong desire and need for culturally matched care and providers who reflect their communities.

What Do Families Want to Learn More About?

FAC members identified topics they want to better understand or explore during future meetings. They include:

- Understanding how disability affects and is affected by a person's other life experiences.
- Navigating processes and tips for managing issues with Medicaid Managed Care Organizations and DDA.
- Home renovation resources to increase accessibility.
- A usable list of allowable items covered by DDA.
- Tips on how to request items, including helpful wording or phrases.
- Help interpret laws and regulations that impact care.

Recommendations

FAC members shared insights and recommendations to improve care coordination across the different systems that serve CYSHCN:

- **Improve communication to prevent gaps in care:** It's crucial to make sure that CYSHCN and their families don't fall through the cracks due to long-standing issues or disconnects between services. Systems and organizations serving them must provide information that is clear, timely, and culturally relevant. This includes using communication methods that address the stigma surrounding disability.

- **Make care coordination more inclusive:** Families would benefit from care coordination that includes parents and caregivers and considers the whole family's needs. It should address the needs of the whole family rather than focusing just on the child's health care.
- **Offer more flexible funding**: Families need more access to unrestricted funding, along with insurance-covered wraparound supports.
- **Increase empathy and awareness:** Care coordinators and other service providers should understand that children and youth with special health care needs have a whole identity and are more than just their diagnoses. Training and exposure can help reduce stigma and improve their care experiences.
- **Revise Home Visiting Process:** Families shared that the current home visiting requirements and in-person visits often feel invasive. They asked for a respectful and trauma-informed approach.

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