

Children and Youth with Type 1 Diabetes

Listening to understand the needs and challenges of families of children and youth with Type 1 Diabetes (T1D) in Washington

KEY POINTS



- Families need more support and resources right after their child's T1D diagnosis.
- Parents find it hard to prioritize their mental health while caring for a child with T1D.
- Schools can help prepare staff better to support students with T1D through education and resources.
- COVID-19 has made it difficult for families to access diabetes care and for clinics to provide it.

In February 2023, the WA State Department of Health invited families of children and youth with T1D to a listening session.

FAMILY EXPERIENCES AND NEEDS

Families often lack resources immediately after their child's T1D diagnosis. They emphasized the importance of receiving more help during this critical time. They also mentioned that it is challenging for them to focus on their own mental well-being while caring for their child. Regularly checking in with parents and other family members can make a difference.

CHILDREN AND YOUTH HAVE UNMET COMMUNITY NEEDS

Schools, including preschools, have the ability to offer their staff more educational resources. Training and information for school nurses, office staff, and teachers can help them better support their students. Teens with T1D need opportunities to make positive social connections. Schools and communities can help connect teens with others living with T1D.



CHALLENGES GETTING DIABETES CARE

The COVID-19 pandemic has increased difficulties for endocrinologist clinics offering specialized care. Some challenges include understaffing and reduced provider availability. The remaining clinic staff are often overworked. The listening session attendees empathized with patients trying to access treatment and medical providers caring for them.



Resources, information, and support for Children and Youth with Special Health Care Needs:
[DOH.WA.GOV/CYSHCN](https://www.doh.wa.gov/cyshcn)

COMMITMENT TO ACTION

Ways the Children and Youth Special Health Care Needs (CYSHCN) team is responding to family feedback:

- **System support groups:** We created 2 groups to address the mental and emotional needs of children and youth with T1D. The [online group for teens with T1D](#), where teens can make positive connections, meets monthly.
- **T1D Statewide Coordinator:** The Department of Health partnered with PAVE to hire a coordinator to support children with T1D and their families. The coordinator also connects them with other families who are at a similar stage of their child's diagnosis.
- **Updated guidelines for student care:** Prioritized the revision of the Guidelines for Care of Students with Diabetes in partnership with the Office of Superintendent of Public Instruction (OSPI) to align with the American Diabetes Association's Helping the Student with Diabetes Succeed: A Guide for School Personnel.

T1D STATEWIDE COORDINATOR

- **Email:** Coordinator@t1dfamilysupport.com
- **Call:** 253-330-9367

Learn more at

- [Type 1 Diabetes Workgroup \(wa.gov\)](#)
- [Diagnosis: Diabetes - Family to Family Health Information Center](#)
- [Washington Type 1 Diabetes Family Support](#)



Questions, comments, concerns?
Contact CYSHCN@doh.wa.gov



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HELPFUL RESOURCES

- [The Juicebox Podcast](#)
- Support groups led by nurses and dietitians
- Community support symposium
- Hearing from those with lived experiences

MORE RESOURCES NEEDED

- Resources about early signs and symptoms of T1D in pediatric offices.
- Training for medical providers around implicit bias and working with BIPOC communities.
- Financial resources.
- Access to mental health services.
- Access to transportation services.
- More health care professional-hosted programs.