

The Catalyst Center is looking for examples of families of children and youth with special health care needs who face inequities in health care coverage and financing

Who is the Catalyst Center?

The Catalyst Center is a national center dedicated to improving health care coverage and financing for children and youth with special health care needs (CYSHCN). The federal Division of Services for Children with Special Health Needs, Maternal and Child Health Bureau, Health Resources and Services Administration, U.S. Department of Health and Human Services funds our work. We work with families, states, and other partners to help ensure families of CYSHCN have access to adequate public and/or private insurance to pay for the services they need. At the Catalyst Center, one of our goals is to raise awareness about inequities in health care coverage and financing for CYSHCN. We accomplish this by learning from families and sharing their stories.

Inequities in health care coverage & financing:

Differences in access to insurance coverage and/or payment for health care based on characteristics such as race, immigration or documentation status, language spoken at home, income, or child's functional status.

Can you help us understand the barriers and highlight the need for reducing coverage and financing inequities among CYSHCN?

Families raising CYSHCN often face challenges getting access to and paying for adequate health care. Our experience in working with professionals and family leaders tells us that this can be particularly difficult for families of color, immigrants and families from diverse cultural backgrounds, those who speak a language other than English, have limited income, or whose child has physical, mental, behavioral, or emotional health needs that greatly affect their ability to do things the same way as other children their age.

Lawmakers and others who shape health care policy don't always realize this. Your story will help policymakers, advocates, and family leaders at the local, state, and national levels learn about the importance of improving coverage and access to care for diverse children and their families, especially those who have faced increased barriers to coverage and paying for services. Your story will help start conversations and may help generate policies that will provide "real world" solutions.

We want to know what works. Please tell us about resources or specific services you may have received that have helped your family overcome barriers. We also want to know about continued barriers you may face, and what more can be done to support your family.

How will the stories be used?

We intend to include these family stories in written materials that can be printed and posted on our website and sent to policymakers, health care providers, family leaders, advocates, legislators and other interested parties. We also may use the information to publish research on outreach strategies to reduce inequities among CYSHCN. Neither your child's nor your family's identifying information will be used without your permission.

We are parents of CYSHCN too.

Meg Comeau, Co-Principal Investigator, and Beth Dworetzky, Project Director, are both parents of CYSHCN; they, and the entire Catalyst Center team, understand that the families who share their stories with us are giving us a gift. We honor your trust and will respect how you want your story to be told. We will protect your family's privacy by leaving out any personal information you don't want us to share and we will only share your story with your consent. Your story can be anonymous.

If you would like to share your story with us, we would like to set up a time to speak with you over the phone and hear about your family's experiences. You can answer all, some, or none of the below questions and/or provide us with any other information you'd like us to know. You can also limit the information you'd like us to share with our partners in any way that feels comfortable for you.

Thank you!

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Questions for families of children with special health care needs who face barriers to health care coverage because of inequities

Background information

Your name (optional):

Your child's name/age (optional):

Tell us about your child's health condition (diagnosis, services/supports that are required or helpful, etc.):

Health insurance coverage and paying for care

1. Before connecting with [organization], what barriers did you face when you tried to get health insurance coverage or health services for your child? Such barriers might include:
 - a. Restrictions based on immigration or documentation status
 - b. Worries about family immigration status
 - c. Concerns about race/ethnicity (e.g., how you or your child might be treated because of your race or ethnicity)
 - d. Language barriers or trouble understanding insurance or other health care information
 - e. Cost of health care
 - i. If this is a barrier for you, what kinds of costs specifically (e.g., co-pays, deductibles, no insurance, etc.)?
 - f. Doctor said child was too complex/didn't have experience to take care of child
 - g. Lack of transportation or the distance to care was too far
 - h. Other?
2. How did [organization] help you overcome these barriers? This might include:
 - a. Clarified immigration regulations
 - b. Understood the specific barriers you faced/provided services that reflected your cultural, language, or other preferences
 - c. Translated materials or provided an interpreter
 - d. Explained coverage options in language that was understandable
 - e. Helped fill out paperwork or otherwise helped you enroll in insurance coverage
 - f. Provided financial assistance or provided information about ways to pay for care
 - g. Helped find a health care provider
 - h. Other?
3. What was most helpful about the assistance that [organization] provided?
 - a. Did the assistance/strategy help you overcome barriers to coverage or access to care for your child?
4. If you still have problems getting or maintaining health insurance and/or paying for services for your child, are these problems because of:
 - a. Immigration status
 - b. Race/ethnicity
 - c. Language barriers
 - d. Providers don't take your insurance
 - e. Not enough specialty providers in area/difficulty finding a provider with experience to care for your child
 - f. No transportation to get to appointments
 - g. Cost is too high
 - h. Confusing paperwork
 - i. Other?
5. What are your ideas for overcoming these barriers or what could be done by the organization or by state or federal policymakers to make it easier for you to get/maintain coverage and/or finance the care your child needs?