

2018 Family Voices Indiana Heart to Heart Conference Agenda

Friday, May 11

8:30 a.m. Welcome & Registration

9:00 a.m. Opening Plenary: Changing the World: The Voice of Family Leaders

10:00 a.m. Break

10:15 a.m. Concurrent Sessions

- Understanding the Funding Maze: Insurance, Waivers and SSI (also offered at 2 p.m.)
- Using Your Medicaid Waiver
- Next Steps After a New Diagnosis

11:45 a.m. Lunch and Exhibit Expo

12:45 p.m. Concurrent Sessions

- Transition to Adulthood
- Care Coordination Tools
- First Steps
- Using Your Medicaid Waiver (offered in Spanish)

1:45 p.m. Break

2:00 p.m. Concurrent Sessions

- Understanding the Funding Maze: Insurance, Waivers and SSI
- Filling the Funding Gaps Where Else is Money for Services?
- Special Education: Advocating for Your Child's Education

3:30 p.m. Exhibit Expo

4 p.m. Conclusion and Evaluation

Saturday, May 12

8:00 a.m. Welcome & Registration

8:30 a.m. Understanding the Funding Maze: Insurance, Waivers and SSI

9:30 a.m. Break

9:45 a.m. Using Your Medicaid Waiver

11:00 a.m. Conclusion and Evaluation

About the Sessions

8:30 a.m. Opening Plenary

Changing the World: The Voice of Family Leaders

Speaker: Rylin Rodgers, Director of Public Policy, Association of University Centers on Disabilities, founding director of Family Voices Indiana and mother to children with special health care needs

Content: The experience of raising a child who have a complex health care need or a disability makes you an expert on systems and services. Learn more about how to share your expertise and experience to make systems work better for children and families.

10:15 a.m. Concurrent Sessions

Understanding the Funding Maze: Insurance, Waivers and SSI (also offered at 2 p.m.)

Speaker: Rylin Rodgers, Director of Public Policy, Association of University Centers on Disabilities, founding director of Family Voices Indiana and mother to children with special health care needs

Content: Children and youth with special health care needs receive a level of health care beyond that of typical kids, and often typical insurance coverage is not enough. This session explores commercial insurance, Medicaid and other coverage available for CYSHCN, Medicaid waivers, and SSI for children and adults with disabilities, and how to understand and access these funding programs.

Next Steps After A Diagnosis

Speaker: Jennifer Akers, Family Voices Indiana Project Director and mother to a child with special health care needs *Content:* When a family receives a diagnosis or their child's diagnosis is unclear, a multitude of questions arise. How do I find reliable information? How do I tell my family? How do I tell my child? This sessions guides families toward finding answers to all of these questions and more and includes an overview of systems and services.

Using Your Medicaid Waiver

Speaker: Heather Dane, Family Engagement Specialist, Indiana Bureau of Developmental Disabilities Services, Riley Child Development Center LEND Family Fellow and mother to children with special health care needs **Content**: This session explores the various kinds of Medicaid waivers in more detail, including the services they provide and ways to make the best use of them for children, youth and adults.

12:45 p.m. Concurrent Sessions

Transition to Adulthood

Speaker: Kerry Bonney, Family Voices Indiana Assistant Project Director and mother to a child with special health care needs

Content: As teenagers with special health care needs approach adulthood they face many changes, including the transition to adult health care. This session discusses how to make the transition from pediatric to adult health care providers, how to help young adults take the lead in managing their care to the greatest extent possible, and what parents need to know about their role in their young adult's care.

Care Coordination Tools

Speaker: Jennifer Akers, Family Voices Indiana Project Director and mother to a child with special health care needs **Content:** Children and youth with special health care needs often access multiple systems and services, including health care, education and community supports. Families can help organize and maximize their children's services and better communicate with multiple providers by creating and continually updating a care notebook and similar tools.

First Steps

Speaker: Erica Walker, Family Voices Indiana Health Information Specialist and mother to children with special health care needs

Content: The first three years of your child's life are so important. Learn more about Indiana's early intervention program including available services, the service plan process, and the transition to preschool.

Using Your Medicaid Waiver (offered in Spanish)

Speaker: Aura Roblero, Family Voices Indiana Bilingual Health Information Specialist, Riley Child Development Center LEND Family Fellow and mother to a child with special health care needs **Content**: Same content as the English version, offered in Spanish.

2:00 p.m. Concurrent Sessions

Understanding the Funding Maze: Insurance, Waivers and SSI (also offered at 10:15 a.m.)

Speaker: Rylin Rodgers, Director of Public Policy, Association of University Centers on Disabilities, founding director of Family Voices Indiana and mother to children with special health care needs

Content: Children and youth with special health care needs receive a level of health care beyond that of typical kids, and often typical insurance coverage is not enough. This session explores commercial insurance, Medicaid and other coverage available for CYSHCN, Medicaid waivers, and SSI for children and adults with disabilities, and how to understand and access these funding programs.

Filling the Funding Gaps

Speaker: Jennifer Akers, Family Voices Indiana Project Director and mother to a child with special health care needs **Content:** Even the best insurance doesn't cover all the expenses of raising a child with special health care needs. Families often don't fully understand what Medicaid or other supports might cover. This session takes a life course approach to addressing transportation, housing, basic needs and more.

Special Education: Advocating for Your Child's Education

Speaker: Rachael Alaniz, MPA, MSW, Family Voices Indiana Health Information Specialist and mother to children with special health care needs

Content: This session explores how to write a vision statement and why it's important to have one, how to understand components of an IEP, and the rights of students with special needs under federal and Indiana special education laws, with a focus on effectively advocating for a child's educational needs.

