

FVLC 2026 Conference Session Schedule



Conference Theme:	Our Voices, Our Stories, Centering Children and Families in Systems of Care		Date: April 15 - 16, 2026	
Opening Remarks and Keynote Presentation	Wednesday, April 15th, 2026 12:00 - 1:30pm ET Presenters: Nakela Cook, M.D., Patient-Centered Outcomes Research Institute (PCORI) Allysa Ware, PhD, Family Voices			
Day 01 Wed., April 15	Well-being and Quality of Life	Equity	Leadership/Other	Policy
Session 1 2:00 - 3:00pm ET	Courageous Parents Network: Palliative Aware Resources for Families and Clinicians Navigating Medical Complexity Presenter: Christina Salley and Kelsey Stanczyk, Courageous Parents Network	Our Voices Matter: Partnering Youth/Young Adults and Families in Healthcare Decisions Presenters: Rachel Shandler, Everett Deibler, and Jeremy Hayer, SPAN	Building Bridges: Community Partnerships That Strengthen Families Presenters: Cindy Weber, SPAN and Tara Szymanek, NJ Family Engagement Network Hub	Parent and Youth Voices in Action: Transforming Systems of Care Through Shared Leadership Presenter: Kathleen Van Antwerp, Jackie Flores-Ortega, Janel Anessa Aguayo, and Kylee Van Antwerp, Partnership for Safe Families and Healthy Communities
Session 2 3:30- 4:30pm ET	Expanding Pediatric Palliative Respite Care Presenters: Robin Blitz, United Healthcare and Susan Agrawal, The Arc of Illinois	The Science of Family Engagement Presenter: Armelle Casau, Family Voices	Redefining Power Dynamics in Pediatric Primary Care Through Co-creation with Family Leaders and System Partners Presenters: Sarah MacLaughlin, ZERO TO THREE and Barbara Ivins & Hope Burt-Williams, Ready, Resilient, Rising! Network, & Roseani Sanchez, Family Voices, & Jenica O'Malley, SUNY Upstate Medical University, & Heather Bushnoe, Early Childhood Alliance	Urgent Action Framework for Humanistic Care: Advancing Partnership, Joy, and Well-being for Children with Medical Complexity Presenters: Bethlyn Houlihan, Center for Innovation in Social Work & Health, BUSSW, and Shawna Parker, Children's Hospital Colorado
Session 3 5:00- 6:00pm ET	Invisible No More: Centering Families Raising Children with Prenatal Opioid Exposure in CYSHCN Systems of Care Presenter: Lenette Serlo, Generation O, The National Organization for Opioid-Exposed Children	Building family leadership in Maui County's early childhood developmental health system Presenters: Maggie Clark, ZERO TO THREE and Jen Cox & Kaliko Kaauamo, Kākou for Keiki (K4K)	Navigating Transition to Adult Life: A Comprehensive Approach for Youth with Disabilities Presenters: Tracie Hayward and Hannah Mathis, Family Connection of South Carolina, & Elizabeth MacInnis, Prisma Health-Midlands Internal Medicine	Being Intentional When Partnering with Families to Reimagine Systems of Care Presenters: Ebonie Zielinski and Erica Sterns, Division of Specialized Care for Children
Awards Ceremony	6:15 - 7:00pm ET			
Opening Plenary: Policy Panel	Thursday, April 16th, 2026 12:00 - 1:00pm ET Presenters: Nancy Netherland, Family Voices of CA; Edwin Park, JD, Georgetown University McCourt School of Public Policy's Center for Children and Families; Alexander Naum, JD, Generation Patient; Wesley Wei, Family Voices			
Day 02 Thurs., April 16	Well-being and Quality of Life	Equity	Leadership/Other	Policy
Session 1 1:30- 2:30pm ET	Families Leading Change: Improving Access to Medical Equipment Together Presenter: Grace Larkins, Family Navigation Network	Language Access in Health Care: Lessons Learned and the Path Forward Presenter: Roseani Sanchez, Family Voices	Patient and family partnership with board certified physicians in the transition to adult care Presenters: Ashley Tomisek, American Board of Medical Specialties, and Joni Bruce, Oklahoma Family Network, & Dan Schulki, Cystic Fibrosis Foundation, & Olivia Ohmer, C.S. Mott Children's Hospital, & Laura Sessums, American Board of Internal Medicine	Family-Engaged Policy Development Presenter: Wesley Wei, Family Voices, Lauren Agoratus, SPAN NJ, & Susan Agrawal, The Arc of Illinois
Session 2 3:00- 4:00pm ET	Moving to Adult Health Care Presenters: Nikki Montgomery, Family Voices, Samhita Ilango, Got Transition, Jane St. John, LifeCourse Nexus, Rachel Shandler, SPAN	Powerful Partners with Purpose: A Full-Circle Journey of Family Leadership Presenters: Amy Clawson, Ohio Family-to-Family Presenter: Amy Clawson, Ohio Family-to-Family	Practical tools for Family Engagement: An in-depth look at the updated FESAT Toolkit Presenter: Andrea Li, Family Voices	5 Fingers of Advocacy Presenter: Sarah Carlson, Family Voices of North Dakota
Session 3 4:30- 5:30pm ET	Building Resilience: Disaster Preparedness for Children and Youth with Special Health Care Needs (CYSHCN) and Children with Medical Complexity (CMC) Presenters: Patricia Frost, National Pediatric Disaster Coalition, & Kaush King, Family Resource Navigators, & Dawn Bailey, Arizona Department of Health Services, & Christian Pulcini, Task force on CYSHCN of Pediatric Pandemic Network, & Darcel Jackson, Children's National Hospital	Partnering to Understand What Matters Most to Facilitate Family Well-Being for Children with Medical Complexity Presenters: Bethlyn Houlihan, Center for Innovation in Social Work & Health, BUSSW and Kathleen Huth, Complex Care Service, Boston Children's Hospital, & Nikki Montgomery, Family Voices	Meaningful Engagement: Centering Family Voices in Academic Conferences Presenter: Dzeneta Dujkovic, AAP, & Morgan Kowalski, Family-Centered Care Taskforce, & Nicole Guysi, Encircle Families	Emerging Family Leaders "Changing Systems, Changing Lives" Presenters: Meghan Chapman, Federation for Children with Special Needs and Nancye Francois-Cajuste, Partnership for Transition to Adulthood