

Current Leadership Opportunities

in North Carolina

Opportunities for NC families to Tell Your Story, Use Your Voice and/or Participate in Leadership Activities:



Your experiences and knowledge as a self-advocate, parent or caregiver of a child with a disability and/or special health care needs are not only unique and important but can also make a difference and positive impact on local, state and national systems.

The Arc North Carolina – The Arc is always looking for families to share stories, get involved with Action Alerts/public policy advocacy, and help us connect families to one another. They also have openings on their Board and various committees. ((Human Rights, Business Development, Housing, etc)

<https://www.arcnc.org/>

Autism Society of North Carolina (ASNC): Our county-based [Chapters](#) are always looking for families and individuals touched by autism – whether as a parent, caregiver, or adult with autism – to lead or participate. Our Chapters are the front porch to ASNC and provide opportunities to support other families as well as build autism acceptance in local communities. ASNC also offers online tools to increase advocacy skills; find them on the [Make Your Voice Heard webpage](#). Keep updated on current policy issues through [blog](#) articles, the Policy Pulse email newsletter, and monthly email newsletters; sign up for the newsletters [here](#). Members of the autism community can also share their experiences and knowledge through [volunteer](#) opportunities, including ASNC’s Human Rights Committee, which accepts applications for non-employees as openings become available.

Decoding Dyslexia – Decoding Dyslexia North Carolina is a non-profit 501 (c)(3), grassroots movement driven by North Carolina families, educators and professionals concerned with the limited access to educational interventions for dyslexia within our public schools. They aim to raise dyslexia awareness, empower families to support their children, and inform policymakers on best practices to identify, remediate and support students with dyslexia in North Carolina public schools. Currently, they are accepting applications for members at large and our open board positions of Vice President and Secretary.

<https://decodingdyslexianc.org/>

Disability Rights NC – DRNC’s communications team is working on a new project called “I belong too.” This project lifts up real stories – *your stories* – about why living in the community is so important to you. #IBelongToo is a DRNC initiative to tell the state why living in the community is important to you or your loved one *in your words*, and to raise awareness about *Olmstead* violations. You have a story to tell! It can be a story of any length. It can also be a word, a sentence, an image, or a short video message. The more stories we have, the louder our message will be. Make your voice heard! Join #IBelongToo

<https://disabilityrightsncc.org/current-campaigns/ibelongtoo/>

Family Support Network of NC Parent Mentor Orientation – FSNNC offers training to parents who have adjusted to their child’s diagnosis and would like to volunteer to provide peer support to families with a newly diagnosed child. Parent mentors listen, offer emotional support, and share community resources with the parent with whom they are matched. For more information, please go to www.fsnncc.org and click on Parent Mentor Orientation. <https://www.fsnncc.org/our-parent-mentor-program>

Family Support Network of Central Carolina - Our mission is to provide support, education, and caring connections to those who have a child with disabilities and special healthcare needs or who have experienced a NICU stay. Family Support Network is seeking parent mentors who would like to connect one on one to help parents with children with disabilities and special health care needs and parents who are interested in facilitating monthly support groups. To learn more about parent mentoring and facilitating support groups email tabia@fsncc.org. www.fsncc.org (336) 832-6507

Local Interagency Coordinating Council (LICC) - Local Interagency Coordinating Councils (LICCs) are community-based advisory groups. Each county should have a LICC. Local service providers and parents work together to make sure that all families know about early intervention services. To find your LICC, Contact NC ICC Coordinator at 919-707-5528 for more information.

<https://bearly.nc.gov/index.php/icc/licc>

Mental Health America of Central Carolinas - MHA provides family support services to parents of children with behavioral, emotional or mental health needs; peer support for adults living with chronic mental illnesses; and mental health education and preventative trainings to the broader community. MHA’s programs bring together mental health consumers, parents, advocates and service providers to address systemic issues impacting mental health. Review current needs on our Volunteer Opportunities page (<https://mhaofcc.org/get-involved/volunteer>), then select opportunities matching your interests, skills, and availability.

NAMI North Carolina -The mission of NAMI North Carolina is to provide support, education, advocacy, and public awareness so that all affected by mental illness can build better lives. Through education, awareness, advocacy, and support, NAMI North Carolina represents the interests of all North Carolinians who are affected by mental health conditions, regardless of age, gender, race, ethnicity, religion, disability, language, sexual orientation, or gender identity. For leadership opportunities, go to: <https://naminc.org/about-us/jobs-volunteering/>

North Carolina Interagency Coordinating Council – The Interagency Coordinating Council (ICC) brings policy makers, service providers, and parents together. It serves young children with disabilities and developmental delays, and their families. Its members work to ensure that the supports and services offered to families are in line with their needs. The ICC meets quarterly in Raleigh. Contact NC ICC Coordinator at 919-707-5528 for more information. <https://bearly.nc.gov/index.php/icc/icc>

NC Child Parent Advisory Council – NC Child’s Parent Advisory Council is an advocacy group of parents and caregivers from across the state whose children rely on Medicaid for their health care. The goal of the Parent Advisory Council is to ensure that the true experts on Medicaid and NC Health Choice have a say in how these critical programs work for North Carolina’s children. **NC Child’s Youth Advisory Council** is currently accepting applications from high school students in Wake and Wayne Counties who are who are interested in promoting social justice, equity, youth leadership, and growing their advocacy skills. To learn more about both Councils, please reach out to La-Mine Perkins, NC Child’s Community Engagement Specialist at lamine@ncchild.org <https://ncchild.org/about-us/our-people/parent-advisory-council/> <https://ncchild.org/about-us/our-people/youth-advocacy-council/>

NC Families United - North Carolina Families United was created around a kitchen table by dedicated parents eager and frustrated to create policy change in schools, medical practices, and their communities that would not only help their children but help those that were to come that struggle with emotional and behavioral issues. The family and youth voice are important at NC Families United. Adult family members with lived experiences have an opportunity to join our board. Please contact our board chair @ boardchair@ncfamiliesunited.org. Youth can be a part of our national Youth Move Chapter by contacting the youth director Lacy Flintall at lf@ncfamiliesunited.org.

NC Health News – NCHN’s mission is to fill the widening gap in media coverage by creating a substantive website that will provide crucial information about health care in North Carolina. They are actively seeking board members. <https://www.northcarolinahealthnews.org/about/our-board/>

NC State Collaborative - The North Carolina State Collaborative for Children, Youth, and Families, through a System of Care framework, provides a forum for collaboration, advocacy and action among families, public and private child and family serving agencies and community partners to improve outcomes for all children, youth and families. They provide a forum for the discussion of issues regarding how agencies, youth and families can work together to produce better outcomes for children, youth and families a “place” where decision makers from agencies can come to work collaboratively to better meet the needs of children, youth and families. For volunteer opportunities find us at: <https://nccollaborative.org/community-collaboratives/>

North Carolina Council on Developmental Disabilities – NCCDD always welcomes the public’s voice. NCCDD looks for feedback from the community and people they serve. They host important listening sessions across the State that encourage people to voice their opinions on disability issues that affect them the most. Applications for Council membership are always welcome and members of the I/DD community, including family members, are encouraged to apply at any time during the year. NCCDD welcomes new, innovative ideas to help accomplish the Council’s goals to improve financial stability for individuals with intellectual and other developmental disabilities (I/DD) and their families, expand community living opportunities and strengthen advocacy in the area of I/DD. <https://nccdd.org/public-policy/take-action-now.html>
NCCDD also offers The Jean Wolff-Rossi Fund for Participant Involvement (Rossi Fund) which empowers people with intellectual and other developmental disabilities (I/DD) and their family members with opportunities to actively participate in decisions that often impact them personally. Through the Rossi Fund, individuals with I/DD and their family members can receive reimbursement for specific expenses for seminars and conferences designed to improve their knowledge, networking and skill levels for advocacy. To learn more and to apply, go to: <https://nccdd.org/initiatives/conference-funding/jean-wolff-rossi-for-participant-involvement-fund.html>

NC Department of Health and Human Services (NCDHHS), Division of Child and Family Well-Being (DCFW), Whole Child Health Section – The Whole Child Health Section offers family and youth partners a variety of opportunities to intersect with and contribute to program planning, implementation, and evaluation. Free trainings are offered to parents of children with special health care needs on many topics including parent leadership and dental home. For more details about the free parent trainings and other resources, visit <https://www.dph.ncdhhs.gov/wch/families/cyshcn.htm>. The Section sponsors family partners to attend national conferences, participate on committees, develop and conduct trainings, review program materials, and other activities. To learn more opportunities available for parents, please email Holly Shoun at holly.shoun@dhhs.nc.gov

North Carolina Department of Public Instruction Council on Educational Services for Exceptional Children -

The Council on Educational Services for Exceptional Children (Council) is established as an Advisory Council to the State Board of Education. “Public comments are an essential and necessary part of CESEC fulfilling its role to advise the State Board of Education with respect to the unmet needs of children with special needs in the state of North Carolina. Stakeholders are encouraged to submit written comments at any time or attend the CESEC’s quarterly meetings and register for public comment. Thirty minutes will be reserved on the CESEC agenda for public input at each meeting. All written comments must be received by at CESEC@dpi.nc.gov or Danyelle Sanders, Exceptional Children Division, 6356 Mail Service Center, Raleigh, NC 27699-6356 by 4 pm, 10 business days prior to the quarterly CESEC meeting. Any comments submitted after that time will be read and/or distributed at a later date.”

<https://ec.ncpublicschools.gov/advisory-council/public-comment>

North Carolina Infant Toddler Program invites all families currently receiving or recently exited from early intervention services to share their story. They may even feature your story on their website, with permission of course. You can email them at beearlync@dhs.nc.gov or click and click on the “**share you story**” graphic at the bottom of their website.



<https://beearly.nc.gov/>

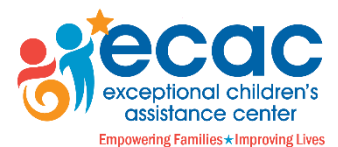
Office of Civil Rights - OCR has announced that it intends to propose amendments to the Department’s regulations at 34 C.F.R. pt. 104, implementing Section 504 of the Rehabilitation Act of 1973. As part of this process, OCR is seeking written suggestions from the public about how best to improve the current regulations. It would be appreciated if longer and more detailed comments were submitted by the end of June 2022, but all comments submitted prior to the issuance of any notice of proposed rulemaking will be reviewed. Send your comments to Section504@ed.gov

<https://www2.ed.gov/policy/rights/reg/ocr/index.html>

System of Care Collaborative of Mecklenburg County - The System of Care Collaborative of Mecklenburg County seeks to work collaboratively with family members, and youth. Our country, state, and county are in the middle of a mental health crisis. Join us today as we open dialogue on School Based Mental Health. Complex issues require collaborative efforts and collaborations require collaborative leadership. We meet on the 4th Thursday of every month via [Zoom 3:30- 5 PM.](#)

For more information, please email ADickey@mhaofcc.org

ECAC Opportunities – Are you interested in submitting your story, or a guest blog or awareness article for our newsletter, website or facebook? Please submit your request to: dhamilton@ecacmail.org



Are you interested in participating in a Focus Group, Family Advisory Board or Parent Panel? Please submit your letter of interest to: kmontague@ecacmail.org

Are you interested in serving on the ECAC Board? Please submit your request to: lweber@ecacmail.org

Are you a youth with a disability and/or special health care need who wants to lead ECAC in designing projects, programs, and resources that are created for youth, by youth? Please contact us at: ecacyouth@ecacmail.org