



SPAN & Family Voices-New Jersey comments on the NJ Council on Developmental Disabilities 2022-2026 Five-Year Planning

April 2, 2021

Thank you for the opportunity to comment on the proposed NJ Council on Developmental Disabilities Five Year Plan. The SPAN Parent Advocacy Network (SPAN) is NJ's federally designated Parent Training and Information Center. Family Voices (FV) is a national network that works to "keep families at the center of children's healthcare." The NJ State Affiliate Organization for FV is housed at SPAN, which is also the home of the Family-to-Family Health Information Center and the NJ State Organization of the Federation of Families for Children's Mental Health as well as the Statewide Parent to Parent program. The Family Voices Coordinator also serves as volunteer for the National Alliance on Mental Illness (including NAMI national restraints committee) as well as NJ representative for the Caregiver Action Network, addressing caregiver issues across the lifespan. Our comments regarding the Council's proposed Five Year Plan for individuals with developmental disabilities follow.

Goal 1: Advocacy

We strongly agree with this as an important goal of the Council. We further agree with the corresponding objectives to increase self-advocacy/civil engagement, decrease barriers to access technology, and address underserved populations (particularly communities of color). For self-advocacy, we would recommend collaboration with CILs (Centers for Independent Living) as well as SPAN's youth activities and initiatives including our Youth Chats, Youth Blog, and NJ YELL (statewide youth leadership council)(see <https://spanadvocacy.org/programs/youth-in-the-know/>).

Goal 2: Systems Change

We also support the goal of systems change improving service delivery. We agree with the objectives to utilize interagency collaboration and address disparities to achieve this. We also agree with the objectives to expand formal/informal supports, especially in the area of behavioral health. We would hope that this also includes health/wellness. Health disparities are known to exist through the lifespan. This includes delays in early intervention, late diagnosis for developmental disability/misdiagnosis based on implicit bias, disproportionate representation in special education classification/segregated settings/discipline, and health care treatment/rationing/discrimination. COVID-19 has exacerbated inequities for people with disabilities. We would recommend collaborating with our PTI and Family-to-Family Health Information Center as well as our related state-funded projects such as the START Project, which develops and supports local special education parent advisory groups to partner with local districts in improving special education services and supports and which now includes the Special Education Volunteer Advocates (SEVA) project originally funded by the Council; NJ Inclusive Child Care Project; Family WRAP (funded by NJ Department of Health to provide support to families of children with special healthcare needs); and leadership development projects such as Empowering Women for Healthy Communities and Parents As Champions for School Health.

Goal 3: Capacity Building

We also support the goal to increase access to services. We agree with the objectives using cultural competency, eliminating restraints/seclusion, improving transition services, addressing medical/behavioral needs (including housing), and dual diagnosis DD/MI (developmental disability/mental illness). In addition to cultural competency, we would also add linguistic competency. Regarding restraints/seclusion, we know that this is ineffective at behavioral modification and experienced as trauma by those subjected to these aversive techniques, often resulting in injury or even death. For special education advocacy, we would again recommend collaboration with SPAN (especially START at <https://spanadvocacy.org/programs/start/>), and for transition, SPAN as well as CILs. In addition to collaboration with the above organizations, we would also recommend looking at evidence based best practices from US Department of Education funded Technical Assistance and Dissemination Centers including SWIFT (inclusive schools, www.swiftschools.org), the Early Childhood Technical Assistance Center (www.ectacenter.org), the National Technical Assistance Center on Transition (see <http://transitionta.org/effectivepractices>), and others.

Thank you again for the opportunity to comment on the Council's Five-Year Plan. We look forward to collaborating with the Council on goals to improve the key areas affecting individuals with developmental disabilities throughout the lifespan.

Sincerely,



Diana MTK Autin
Executive Co-Director, SPAN

35 Halsey St., 4th Fl., Newark, N.J. 07102
(800) 654-SPAN ext. 105
Email diana.autin@spannj.org

Website www.spanadvocacy.org



Lauren Agoratus, M.A.-parent
NJ Coordinator- Family Voices @ SPAN

35 Halsey St., 4th Fl., Newark, N.J. 07102
(800) 654-SPAN ext. 110
Email familyvoices@spannj.org

Website www.spanadvocacy.org

To empower families and inform and involve professionals and other individuals interested in the healthy development and education of children, to enable all children to become fully participating and contributing members of our communities and society.