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Statewide Parent Advocacy Network, Inc.

Empowered Families: Educated, Engaged, Effective!

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Testimony of Family Voices-NJ and SPAN on the NJ Early Intervention System Family Cost Participation Policies and Procedures 8/13/10

Thank you for the opportunity to comment on the proposed increases in the family cost share for early intervention. The Statewide Parent Advocacy Network (SPAN) is the federally designated Parent Training and Information Center, Family-to-Family Health Information Center, and home for both Family Voices/Family to Family Health Information Center and Parent-to-Parent. We were deeply concerned when family cost share was first instituted in our state, and are concerned now that the family's share will increase significantly. Families of children with special needs cannot afford extra expenses in addition to what they are already experiencing.

I had previously commented as a parent during the last increase in the family cost share. My story is illustrative of some of the challenges that even middle-class families face raising children with disabilities and special healthcare needs.

Despite the fact that both my husband and I worked, we almost lost our home due to lost wages and medical bills when our daughter was born with multiple disabilities. It took us years to recover financially and at times my husband worked full-time and I had two fulltime jobs, including evenings and weekends. Our financial struggles continue to this day. Our most recent out-of-pocket expenses calculated for three years of therapies not covered by the school or insurance was \$45,000 (average \$15,000 year). I anticipate this will increase as we are now currently receiving biweekly bills from Children's Hospital for \$12,000 (\$900 out of pocket) for just one of three specialists as she is pre-transplant. She is also on multiple medications, including injections, which is costly but will actually increase to 16 medications post-transplant.

If there had been a family cost share when my daughter was in early intervention, we might not have been able to get services for my child. I am extremely grateful that she did benefit from early intervention as we later received a secondary diagnosis at age 7 of autism. I am convinced that if my daughter had not received early intervention she would be "classically" autistic as opposed to high functioning autism/ Asperger Syndrome today. I don't know what her health condition would have been if we hadn't received help as she wasn't initially expected to survive. Again, had there been a family cost share during this financial crisis time for our family, we would not have been able to get her the help she needed.

As an advocate, I urge the Department of Health and Senior Services, Governor Christie, and the New Jersey Legislature to find other funding sources for early intervention. Research has shown that early intervention is the key to better outcomes for children. Families need to be able to support their children to reach their best potential. These are the very families that are the most financially unable to pay more because they already have extraordinary expenses.

We appreciate that the budget was looked at across domains and that provider rates were decreased by 5% so that there is sharing of the proposed burden rather than having the entire burden fall on families. However, we are concerned that reducing provider rates may result in decreased availability of service providers, especially in areas where there are already personnel shortages.

We agree that the family's co-pay should never exceed the cost of service.

We share the concerns of other advocates, including ABCD and Disability Rights New Jersey, that lowering the income threshold for the Early Intervention family cost share will seriously impact the ability of families to receive necessary services. When the family cost share was first implemented up to 7% of enrolled families left the Early Intervention System. Sadly, many of these children went without the services their children needed.

We are concerned that the percentage of the FPL (federal poverty level) will be lowered to 300% for families to avoid being subjected to cost sharing. The FPL is not adjusted for actual cost-of-living in the state; New Jersey has one of the three highest costs of living in the country, so 350% of the FPL reflects a realistic picture of what "low-income" looks like in our state.

We are deeply concerned that the proposed guidelines disproportionately affect families of lower income. The new cost share will start at income levels of \$44,000/year. In addition, the cost share will be \$1 more per hour starting at \$50,000/year and \$60,000/year. But then it is actually \$1 less per hour in most increments starting at the \$70,000 mark up to \$190,000/year. Then for the \$200,000 and above, the cost share is the same. So the lowest income families who can least afford it are paying more, higher income less, and the highest income families have no cost increase.

We are especially concerned that families of children with the most significant disabilities in need of the most services will be especially hurt by any proposal to change the Family Cost Share because of the relationship between family cost share and cost of services.

Other possible solutions would be to identify children eligible for Medicaid/SCHIP/New Jersey Family Care. Census data indicated there were over half a million children eligible for FamilyCare but not yet enrolled. Recently, an additional 13,000 legal immigrant parents also lost coverage, affecting many children. Also, insurance companies should have parity for children's services, but up to 75% of NJ's plans are exempt from state regulations due to ERISA (Employee Retirement Income Security Act) which was originally meant to be a *protection* for families, not used as a loophole for insurance carriers. (In fact the new autism coverage only applies to 25-30% of families due to this loophole.)

We agree with the Association for the Betterment of Citizens with Disabilities and the Early Intervention Providers' Association in their letter to Commissioner Alaigh: "Creating a financially sound early intervention program requires the injection of additional revenue sources. Pursuing private health insurance coverage, completing the transition to a fee for service system, and increasing operational efficiency are three methods of stabilization. Private health insurance

coverage alone will net between \$10 and \$15 million – an amount more than adequate to compensate for the recent cut. Transitioning the remaining grant funded portions of the system to fee for service will see a long term savings as productivity and efficiency improve. Operational enforcement of the family cost share payment, easier payment methods for the cost share, and matching reported family incomes with tax records are just a few of the systems efficiencies that will increase revenue.” Seeking reimbursement from private health insurance is a more attractive option now that federal healthcare reform prohibits lifetime caps on benefits for children.

The most important consideration for us, and for the state, is the fact that not adequately funding early intervention will result in additional expenses for special education and other services from other state systems if young children don't get the help they need now because of increases in family cost share or reduced provider availability due to reductions in provider reimbursement rates. The last time the cost share was increased, many families opted out of services. Most importantly, the health of children will be negatively impacted if they do not receive early intervention resulting in poorer outcomes for children and their families. SPAN looks forward to working with the Department and the Governor's office to identify additional funding sources for early intervention so that the state budget is not balanced on the backs of families who already face budget balancing acts due to the costs associated with raising their children with disabilities and special healthcare needs.

Thank you again for the opportunity to comment on the proposed family cost share for early intervention.

Sincerely,

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