



FLORIDA DEVELOPMENTAL DISABILITIES COUNCIL, INC.

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Children with Disabilities Who Have Medically Complex Conditions

The Council supports family life for children with medically complex conditions and the services that will enable all of these children to live, grow and thrive in a home with a family.

The United States Department of Justice report of 2012 and subsequent lawsuit has led many organizations, individuals and state agencies to examine the current service delivery system for children with medically complex conditions. The state agencies involved in the care of children with medically complex conditions (Agency for Health Care Administration, Agency for Persons with Disabilities, Department of Children and Families, Department of Education, and Department of Health) have taken a number of steps to address the goal of transitioning Medicaid-eligible children who reside in a skilled nursing facility into a home or home-like setting, and to ensure that Medicaid-eligible children who do live at home are not at risk of being institutionalized.

However, much more needs to be done. In Florida, there are still 150 children with medically complex conditions living in skilled nursing facilities (30 with active transition plans). While skilled nursing facilities can provide needed interim intensive medical care to stabilize a child, they should not be a child's long term or lifetime home. Children need to grow up with the emotional security and continuity of a parental relationship and a stable living arrangement. Families need to know that the services will be there to support them and their child in the home. This requires Florida putting adequate resources in place to support these families. Families also need services that will not only address their child's medical needs, but will address the child's need for nurturing, love, belonging, security and safety that a consistent, committed adult/child relationship provides.

The Council encourages the State of Florida to continue to improve the options available and to consider the following recommendations to strengthen the service delivery system to support the care for children with medically complex conditions and ensure families have the necessary support to provide care at home.

- **Adopt a state policy that facilitates a permanent living arrangement with a family providing an enduring and nurturing parental relationship**

Placement in a skilled nursing facility should always be considered temporary. A family should be considered the surest and most effective way to meet a child's basic needs for safety, security, and stability. An individualized permanent living arrangement with an enduring and nurturing family should be developed. This is an on-going planning process that should be reviewed with the child's family every 6 months and work with the child's family to understand their needs and desires for their child and the child's future. Specifically, the process should consider the development of a comprehensive family plan to either bring the child home or to provide a support family that will meet their goals. Parents retain the right to decide whether the child is placed in or remains in the skilled nursing facility. However, it should be the policy of the State that a skilled nursing facility placement is temporary.

- **Family-Based Support Homes**

Services available through a waiver for children with extensive medical needs should include a family-based support home instead of a skilled nursing facility for families who decide that they cannot care for their child with medically complex conditions in their home. A support home is a family setting in which the family provider is specially trained to provide support and in-home care for children who have medically complex conditions. This home would be different than a traditional group home in that the family would be the provider for one to three children with complex medical needs and not paid shift staff. These families are carefully and specifically identified for each child, starting with the family's circle of support. Birth families are the final decision makers of the families chosen and should

develop agreements with the support families covering the roles, responsibilities and interactions with the child.

- **Provide Adequate Medicaid State Plan and Waiver service options for Children who have Medically Complex Conditions.**

There are children who have medically complex conditions that do not meet the eligibility requirements for Medicaid (unless services are provided in the skilled nursing facilities) or are on a waiting list for Medicaid Waiver services. For families receiving Medicaid State Plan and/or Medicaid Waiver services and caring for their children in their homes, the availability of nursing services is often insufficient, due in part to the reimbursement rates and the availability of nurses with the appropriate experience to serve children with medically complex conditions. There should be an array of services in place and qualified providers that will allow the child to remain at home and prevent placement in a skilled nursing facility. Toward this end, the state should:

- Develop and implement either an expansion of its Model waiver or a new waiver that enables children with medically complex conditions to receive Medicaid coverage to be cared for at home or in a home environment.
- Require that the funding being used to serve children in the skilled nursing facilities follow those children to cover the services needed in the home and community.
- Establish a higher Medicaid State Plan reimbursement rate for nursing services for children who have medically complex conditions and expand the pool of available nurses to also include independent nursing providers with experience caring for children with medically complex conditions.

- **Facilitation of a Permanent Living Arrangement and Transition to Family Homes**

The successful transition and placement of children in the homes of their birth families or their support families begins with the establishment of a relationship with the family and discussing all possible options. This occurs through frequent contact with the families as part of the permanent living arrangement dialogue. It continues with the identification of the appropriate support family (if the goal of the birth family), coordination of training of the birth or support family, and coordinating the state and local resources that will provide the needed support as identified by the family. The implementation of permanency planning and transition to a family home requires a facilitation entity and a locus of responsibility that spans multiple state agencies and local providers.

- **Ensure Transition of services when a child turns 21**

Provisions should be in place to ensure that children will have the continuity of care in the family home or the Support Family home after the child turns 21.

