

Comments from the Imagine Different Coalition on the Proposed Amendments to the Consolidated and Person/Family Directed Support Waiver

Our concern

The statewide Imagine Different Coalition is concerned about the nearly 3,000 PA children with developmental disabilities under age 21 living in congregate settings. Family life is essential for all children to promote physical, cognitive, social and emotional growth and development. It is a well-researched developmental imperative for children to grow up in families with the constant enduring relationships of caring adults. For children with disabilities it is vital to their development. Right now, children with disabilities living in congregate care facilities, especially those without the resources available to children with Intellectual Disabilities (ID), have few pathways to family life.

This is contrary to DHS's intentions as we understand them. The changes being considered by the ODP to the Home and Community Based Services (HCBS) waiver: 1) do not provide waiver availability for children with ID living in institutions; and 2) do not take into consideration the need for waivers for all children under age 21 with all types of developmental disabilities living in or at risk of admission to long term care facilities, and lack long term and adequate services and supports

The role waivers can play

Waiver services have an important role to play in addressing this concern for a number of reasons. Early and Periodic Screening, Diagnosis and Treatment (EPSDT) resources do not cover all the services needed by children and adolescents with developmental disabilities to avoid institutionalization: services such as respite, home modifications and residential habilitation (e.g., life-sharing or partner families). Currently, children with ID who are living in institutions are being denied emergency priority to receive waiver services. Also, children under 18 who have developmental disabilities other than ID (cerebral palsy, spina bifida, complex medical conditions requiring trachs or ventilators, etc.), as well as infants and toddlers with ID, have no access to waiver-funded respite, home and vehicle modifications or residential habilitation. Parents who find themselves unable to care for their children at home currently have no option but to accept the placement of their child in a nursing or other institutional facility. With access to HCBS waiver services, these children could be living in families

Ensuring family options for children with ID

The proposed amendments do identify areas where waiver capacity needs to be expanded. However, they fail to address the issue of children growing up in institutions. We strongly recommend that ODP add reserve capacity in the PFDS waiver for children who could return to their family homes from institutions if they had respite and/or home modifications, and add reserve capacity to the Consolidated waiver to move children from institutions to Life-Sharing, with parent or guardian permission, if they cannot return to their family homes.

We also urge ODP to lower the age of eligibility for ID waivers to birth. Tragically, there are infants and toddlers currently living in facilities due to lack of necessary supports. As with EPSDT, the Early Intervention waiver does not provide home modifications, respite or Life-Sharing.

Finally, exceptions should be made to the limitations on home modifications identified in the current and proposed ID waivers when necessary, when such exceptions can avoid the institutionalization of children. Children should not be growing up in institutions, away from their families, simply because the family cannot find or afford a home that is accessible to the child.

Children with Other Developmental Disabilities - Options to consider

We offer the following options for your consideration. We strongly recommend that DHS create a single waiver for all children with developmental disabilities, starting at birth: a waiver that includes a variety of alternative family living options, such as Life-Sharing run by the Department (through ODP), rather than by managed care.

Alternatively, DHS might lower the age eligibility of the current ID waivers to birth and include in those waivers children with other developmental disabilities who meet the ICF-ORC level of care.

Lowering the age of the OLTL waivers and the new CHC program would be another, albeit less promising, option.

Regardless of which path the Department takes, funding of the services needed to assure family life for children must be a priority.

Submitted by:

Dianna Ploof
Kenneth Oakes
Co-Chairs
Imagine Different Coalition