

## Comments from the Imagine Different Coalition on the Proposed Amendments to the OBRA Home and Community Based Services (HCBS) Waiver

**For the reasons described below, the Imagine Different Coalition requests that DHS:**

- 1) Ensure that children with any kind of disability who are living in, or at risk of being placed in, long-term congregate care, have access to Home and Community Based waiver services, by lowering the age of the OBRA waiver to birth or creating a new children's waiver.**
- 2) Add Life-Sharing / Partner Families to the OBRA waiver;**
- 3) Clarify the language in the waiver application to ensure that individuals under 21 who currently or in the future are enrolled in or eligible for any of the OLTL waivers can enroll in the OBRA waiver; and**
- 4) Allow exceptions to the limitations on home adaptations currently in the OBRA 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 our understanding of DHS's intentions. The changes being considered by the DHS to the OBRA waiver do not take into

consideration the need for waivers for children under age 18 with developmental disabilities other than ID, living in or at risk of admission to long term care facilities, and lack of 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 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 child 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.

### **Options to consider**

We strongly recommend that DHS create a single HCBS waiver for all children with developmental disabilities at risk of institutional placement, starting at birth: a waiver that includes a variety of alternative family living options, such as Life-Sharing run by the Department (through ODP).

Alternatively, lowering the age of the OBRA waiver to birth and adding Life-Sharing/Partner families would be another option.

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

### **Transition Age Youth**

It is our understanding from Brendan Harris that DHS has agreed to retain the eligibility of youth ages 18-21 in the OBRA waiver, and to transition

youth currently served by other OLTL waivers into OBRA. We thank you for this and recommend that you restate the last paragraph of Attachment #1 to the “Main Module” to read:

The OBRA 1915(c) waiver will ~~[strike out “not”]~~ be operated concurrently with Community HealthChoices. Those waiver participants who do not meet nursing facility clinical eligibility, ~~or the age requirements of the CHC,~~ will either remain in the OBRA or be transitioned to a more appropriate DHS waiver or state program, depending on their assessed needs. It is the Department of Human Services’ intent to ~~[strike out “reduce”]~~ ~~change~~ the number of individuals served through the OBRA waiver. The Department will maintain ~~[strike out “a small number of”]~~ ~~enough~~ “slots” so that individuals who do not meet the CHC Waiver eligibility requirements either do not lose services (current enrollees) or access to services (future enrollees). ~~In addition, the Department anticipates transferring all 18-21 year olds who are currently enrolled in other OLTL waivers into the OBRA waiver. If these recipients are eligible for the CHC when they reach 21, they will be transitioned at that time. If not, they will remain in the OBRA Waiver.~~

### **Home Adaptations:**

Finally, exceptions should be made to the limitations on home adaptations identified in the current and proposed OBRA 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.

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