



## *Imagine Different... Achieve Different Coalition*

### Position on Children with Disabilities Growing Up in Congregate Care Facilities

Hundreds of Pennsylvania children with complex medical, behavioral and developmental disabilities are growing up in segregated congregate care facilities. The Imagine Different Coalition wants to change that. We believe that all children should and can grow up in families. The Coalition represents a large group of advocates, individuals with disabilities, families, and organizations dedicated to ensuring that children with disabilities have the opportunity for family life. The substantial combined experience of Coalition members, as well as our research, convinces us that family living is possible for all children. We seek to collaborate with government and the community to achieve family life as an alternative to congregate care for children with disabilities.

#### **Imagining different—family life instead of congregate care**

Our convictions about the importance of family life are based on experience, research, legal requirements, demonstrations in other states, and pragmatic possibilities in Pennsylvania.

Our experience. We have seen that the needs of children with disabilities and long term health or behavioral concerns can be effectively addressed within the context of everyday family life. We recognize that there are facilities that provide good medical care, kind staff and child-friendly environments (and some facilities that do not), but family life cannot be provided in a facility. We understand that some parents and professionals feel that children need facilities with skilled staff. We acknowledge that short-term, acute-care, hospital or rehabilitation facility services and supports are sometimes necessary. However, we have seen how long-term services can be provided in family homes in ways that better meet children's overall developmental needs.

Research findings.<sup>i</sup> We have learned from research that children benefit most when growing up within well-supported families. Child development research provides scientific evidence about the significance of early experiences and the central role of parenting relationships for optimal development. Neuroscience research confirms the growth-fostering importance of close relationships for brain development in young children. Historical and contemporary research comparing institutional-reared children with family-reared children has consistently found poorer outcomes in congregate care. Conversely, little rigorous research has found that residential group care is more effective than family-based care. Research shows that families' decisions to place a child in congregate care are often constrained by external factors such as income,

availability of extended family caregivers, government policies, interactions with professionals, and the way services are organized. In particular, research has identified that parents of children with disabilities have lower incomes and higher out-of-pocket costs related to their children's care needs compared to parents of other children. In summary, research shows that although children benefit substantially from growing up in families, external factors counterproductively leave families at risk of having to seek placement in congregate care for their children with disabilities.

Legal requirements. We believe our efforts are consistent with legal protections for people with disabilities. By federal law, children and adults with disabilities must be offered services in "the most integrated setting appropriate" to their needs.<sup>ii</sup> A Supreme Court decision known as "Olmstead" requires states to have a plan to offer community options to residents of institutional settings.<sup>iii</sup> For children who have been abused, neglected or abandoned, additional federal and state laws require placement in a safe setting that is the least restrictive and most family-like appropriate to their best interests and special needs.<sup>iv</sup> We believe supported family living represents the most integrated, least restrictive, and most appropriate setting for all children.

Research about other states. We have learned how other states successfully enable family life for children with disabilities. With funding from the Pennsylvania Developmental Disabilities Council, a series of workbooks has been developed that explain how family alternatives to congregate care have worked successfully in other states and how families who initially chose institutional care for their children have been helped to imagine possibilities for family life for their children and then achieve it.<sup>v</sup>

Practical possibilities. The Commonwealth devotes a great deal of resources to congregate care that could be utilized differently to support family life. Pennsylvania provides some supports to families and children, but for too many families support is not available, not adequate, not known, or not utilized well enough to prevent admission to congregate care or enable return home. Pennsylvania provides family-based alternatives such as Life-sharing<sup>vi</sup> and Medical Foster Care<sup>vii</sup> that could be more fully utilized, adapted, and expanded to enable family life for children growing up in congregate care settings who cannot return or remain home. With adequate supports these and other family living arrangements could assure a family<sup>viii</sup> home for every child.

## **Imagining different—support when families need help to raise their children at home**

We believe Pennsylvania can organize and align its resources so as to help families raise their children in their own homes. For some families, Medical Assistance provides extensive supports, but it is not always enough. For children who need significant round-the-clock care, services such as respite, home renovations, rent subsidies, and

other supports not covered by Medical Assistance can be critical, especially to low-income families, single-parent families, and parents who have no local extended family support.<sup>ix</sup>

Brian, age 12, is a young boy who had a traumatic brain injury that resulted in extensive loss of functioning and ongoing medical needs. He was placed in a facility for medically fragile children. His family loves him and desperately wants to care for him at home. When he was ready for discharge from the facility, the family's housing—the only place they could afford to live—was found inadequate for his care. As a result, Brian was referred to the child welfare system. His family did not want to lose custody and asked for help to either fix their home or rent a new home where they could care for the child they love. Neither the disability system nor child welfare system provided housing assistance, so Brian remains in an institution unnecessarily where the state pays not only for his housing but also for personal care services, meals, and much more that his family would have happily provided.<sup>x</sup>

Across Pennsylvania's child serving systems we need to critically examine how to better use and organize our resources to assist families to raise their children at home.

Some children's stories are as yet untold. We know there are families whose children are growing up in institutions because they don't know there are alternatives. Some families placed their children when alternatives weren't available. Others placed their children because they simply weren't aware of ways to build supports using the current system. Once placed, no established process exists to explore alternatives.

We respect families' decisions to place in congregate care as being the best they could make at the time, but we believe with outreach and well-informed support those families could be helped to explore a different alternative—a way for their child to return home with supports they couldn't imagine or achieve when they placed their child.

### **Imagining different—family-based alternatives when families need options**

When it is not possible for a child to remain in their birth or adoptive family home full-time, we believe resources could be organized to be able to offer family-based alternatives such as “partner families.” A partner family arrangement is a voluntary agreement where another family is supported to share their home with a child on either a part-time or full-time basis, and to share child-rearing and care responsibilities and joys with the child's family. This type of shared parenting is not an atypical arrangement—children with and without disabilities are often cared for in two homes (divorced parents, grandparents, or aunts and uncles). For children with complex needs, a two-family arrangement where the families work together can improve the lives of all concerned and prevent the need for institutional placement. We have learned how

this model works in Texas, and believe it can work in Pennsylvania too.<sup>xi</sup> In Pennsylvania, children remain in congregate care facilities because this kind of alternative is not readily available within the current system.

Tommy and Sam are brothers, both with intellectual and developmental disabilities and significant medical needs. Their single mother also has a disability. Home-health services were approved for the children but nurses and aides were either unavailable or not consistently available to provide the level of support that Tommy and Sam needed. Without adequate support to care for her sons on her own, their mother felt she had no alternative but to place them in facilities. She would prefer that they grow up in a loving family. She could imagine a partner family arrangement whereby she could share care part time with another family and still play a major parenting role in her boys' lives. But the boys remain in an institution because this different alternative has not been imagined or achievable within the current system.

Within the child protective services system, better-supported foster care could enable family life for children with disabilities otherwise growing up in congregate care.

Lisa is a young woman with a physical disability and chronic respiratory condition. She uses a wheelchair and needs physical assistance with all activities of daily living. She is fed through a tube in her stomach, uses medical equipment to assist her breathing, and needs monitoring of her health needs 24 hours a day. As a child, when her mother was not capable of caring for her safely, she was placed by the child protective services system in an institution. For seven years, Lisa repeatedly asked to move to a family where she could have a typical social life. When she became an adult, the disability services system made it possible for her to move to a home in the community with long term services and supports. Had the services and supports in the adult community home been imaginable and available to a foster family when Lisa was young, she would not have had to spend her childhood in a facility.

Pennsylvania policies, practices, and resources could be better applied to support children with disabilities in a family home when they cannot return or remain home.

### **Achieving different—family alternatives to congregate care**

The first step to change is imagining alternatives. The second step is working together to achieve them. We can imagine many avenues to achieve family life for Pennsylvania's children. We believe Pennsylvania can develop (1) better support to enable children to return home or prevent admission to congregate care, (2) viable mechanisms to support other families for children who cannot return or remain in their birth or adoptive family homes, (3) an outreach strategy to engage families of children

growing up in congregate care to imagine different possibilities, and (4) a comprehensive plan across state agencies to track and plan for all children with disabilities growing up in congregate care. We are committed to further develop ideas for change and offer details for consideration. We seek to collaborate with government and the community to Imagine Different options for Pennsylvania’s children and families and work together to Achieve Different results—family life instead of congregate care for children with disabilities.

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<sup>i</sup> For a lengthy review of literature see Congregate Care for Children with Disabilities: Understanding Children’s Needs, Stakeholder Perspectives, Alternatives and Opportunities. Literature Review. N Rosenau (2006). Available from the PEAL Center. [www.pealcenter.org](http://www.pealcenter.org)

<sup>ii</sup> See 28 C.F.R. § 35.130(d)

<sup>iii</sup> *Olmstead v. L. C.*, 527, U.S. 581 (1999)

<sup>iv</sup> Social Security Act at 42 U.S.C. §§ 675(5), Juvenile Act at 42 Pa.C.S. 6351

<sup>v</sup> See Imagine Different . . . Achieve Different! Set of three workbooks available from the PEAL Center. [www.imaginedifferent.org](http://www.imaginedifferent.org)

<sup>vi</sup> For a description of Life-sharing in Pennsylvania see the DPW website at <http://www.odpconsulting.net/topic-info/lifesharing-everyday-living-options/#.VATHufIT6fU>

<sup>vii</sup> For information about Medical Foster Care in Pennsylvania see [http://www.pccyfs.org/Calendar\\_Details/special\\_medical\\_foster\\_care\\_special\\_transmittal.pdf](http://www.pccyfs.org/Calendar_Details/special_medical_foster_care_special_transmittal.pdf)

<sup>viii</sup> Families can take many forms (nuclear, extended, multigenerational, parenting shared across multiple households, foster families, adoptive families, families that come together through programs like Life-sharing and Medical Foster Care). Common to all healthy and safe families is the presence of at least one (and often more than one) loving adult committed over the long term to nurture, guide, and assure a secure everyday home life throughout a child’s life.

<sup>ix</sup> For a comprehensive analysis of the barriers to serving children in their own family homes see Ordinary Lives, Extraordinary Needs: Assuring Family Life for Children with Complex Healthcare Needs (2006). Available from the PEAL Center [www.pealcenter.org](http://www.pealcenter.org)

<sup>x</sup> The scenarios in this position paper are based on the experiences of actual children but names have been changed to protect privacy.

<sup>xi</sup> See endnote v