



Policy Brief – Children in Texas State Institutions

The Issue

Texas has more children in state institutions for people with intellectual disabilities (previously known as mental retardation) than any other state in the nation. Decades of child development research has indicated that institutionalizing children in large congregate settings negatively impacts all areas of their development including physical, intellectual, psychological, and emotional growth.

The research tells us that relationships are among the most significant influences on healthy growth and psychological well-being. Over and over again, child development research points to the fact that of primary importance to a child's physical, emotional, and psychological development, is a close, nurturing, consistent relationship with the parent(s) or surrogate parental figure – a consistent and predictably available adult. *This relationship offers the safety and security that shift staff in large institutions cannot provide.*

The Research

Illustrating the common thread of child development research compiled over the past several decades, the National Research Council published a report in 2000 titled *From Neurons to Neighborhoods*.¹ This report was the result of a 2 ½ year project during which 17 recognized experts from the National Research Council evaluated and integrated the current science of early childhood development. Their charge was “to update scientific knowledge about the nature of early development and the role of early experiences, to disentangle such knowledge from erroneous popular beliefs or misunderstandings, and to discuss the implications of this knowledge base for early childhood policy, practice, professional development and research.”²

The report was approved by the Governing Board of the National Research Council whose members are drawn from the National Academy of Sciences and the Institute of Medicine.

The following excerpts from this report are directly relevant to the discussion regarding the impact of institutionalization on children:

1. “The scientific evidence on the significant developmental impacts of early experiences, care giving relationships, and environmental threats is incontrovertible...The science of early development is also clear about the specific

importance of parenting and of regular care giving relationships.”³

2. “Nurturing, stable, and consistent relationships are the key to healthy growth, development, and learning...”⁴
3. “Children growing up in institutions have been the focus of a long standing literature on early privation ... This literature tells a compelling story about the severe developmental consequences of institutional care that affords neither stimulation nor consistent relationships with caregivers...It also reveals the remarkable recovery that characterizes many children exposed to these environments once they are adopted into loving homes, as well as the long-term impairments that continue to plague some of them many years after their life circumstances have improved. On both accounts, the fundamental message concerns the vital importance of consistent and committed adults in young children's lives.”⁵
4. “Children who spent more time in the institutions showed more persistently poor outcomes.”⁶
5. “Those adults who are most consistently available and committed to the child's well-being play a special role in promoting competence and adaptation that cannot be replaced by individuals who are present less consistently or whose emotional commitment is not unconditional. Young children who do not have a relationship with at least one emotionally invested, predictably available caregiver – even in the presence of adequate physical care and cognitive stimulation – display an array of developmental deficits that may endure over time.”⁷

The nurturing, consistent, and predictable relationship offered in a family cannot be duplicated by shift staff available for limited hours each day and a limited number of days each week.

In recognition of the significance of the research and the need to address the problem of institutionalization of children with disabilities, the Centers for Disease Control and Prevention (CDC) has recognized the importance of children growing up in families and included in their Healthy People 2010 recommendations a specific objective relating to the deinstitutionalization of children with disabilities.

Objective 6.7b. – Reduce to zero the number of children aged 17 years or younger living in congregate care facilities.⁸

(Note: The CDC definition of congregate care: Settings in which children or adults with disabilities live in a group of four or more people with disabilities, in order to receive needed supports and services.)⁹

In justification of this goal, the Healthy People 2000 Progress Review states the following:

“Institutions and other forms of congregate care are inconsistent with positive public health policy and practice...The goal, therefore, is to increase the number of people in non-congregate family and community settings where the services and supports they need are made available.”¹⁰

“Congregate placements for children should be ended within the decade, if not sooner, consistent with the Statement in Support of Families and Their Children.”¹¹ (The statement can be found in Rosenau, 2000¹²)

Positive Efforts Made in Texas to De-institutionalize Children with Disabilities

Texas began addressing the issue of children with disabilities in institutions almost a decade ago. In some respects significant progress has been made. In other respects, however, Texas is regressing. Permanency planning requirements created in SB 368 (Zaffirini, 77th) have increased the attention paid to institutionalized children and have emphasized the importance of children growing up in families. Statute requires that permanency planning (a comprehensive review of the child and barriers to family life), occurs every six months. Recognizing the harmful effects of institutionalization on children, the intent of permanency planning is to ensure that every institutionalized child is able to return to a family as soon as possible.

Two specific initiatives required by statute directly address the needs of children with disabilities residing in Texas institutions. The initiatives include permanency planning and the family-based alternatives project.

Statute now requires permanency planning for children institutionalized in nursing facilities, intermediate care facilities, state schools, and group homes be reviewed every six months. This is intended to ensure that ongoing attention is paid to the barriers that prevent these children from

growing up in families.

Additionally, the family-based alternatives project (also established in SB 368) has taught us how to develop sustainable family-based options to institutionalization.

The Texas Health and Human Services Commission reports that since the inception of the SB 368 family-based alternatives project and the enhanced permanency planning requirements, approximately 1,000 children have left institutions and are now growing up with either their birth family, a support family, or with a foster family. Additionally, over 700 children have left large ICFsMR and have moved to smaller less restrictive group homes or small ICFsMR.¹³ This is the good news.

Where Texas is Failing

The very bad news is that the front door is still open and children continue to be admitted to institutions. Especially troubling is the number of children admitted to state schools over the past few years. At the end of 2006, there were 270 children in state schools. During 2007, 36 of those children transitioned to community services. Approximately 85 came off the “children rolls” and moved to adult services, but most of the 85 stayed in the institution. **The disturbing news is that during FY 2007, 152 new admissions of children took place during that one year.** Thirty-six children left state institutions, but 152 children went in. The latest statistics from HHSC is that there are now 301 children under the age of 21 in our state institutions.¹⁴ Twenty-four of these children are under the age of 13 years with some as young as 8 years old. Something must be done to stop this trend.

Recommendations

There is no single, simple solution. Eliminating the institutionalization of children in large state institutions will require doing more than we've done in the past as well as doing things differently. Any institutionalization or potential institutionalization of a child should be considered a crisis and should be treated as one. The current infrastructure and culture does not view institutionalization of a child as the emergency it is. The following recommendations are intended to change how the system responds to the institutionalization of a child with disabilities:

- 1. Know the harmful affects of institutionalization; prevent the placement of children under the age of 18 years in state institutions.**

2. **Make available the resources and flexibility needed to provide the services that will prevent institutionalization.** Create mechanisms so that the funding being used to pay for institutional services for children can be used more flexibly to address the crisis to prevent or minimize the length of institutionalization.
3. **Develop and implement accountability measures for quality permanency planning.** (Currently, there is no system for quality review of individual permanency plans and no analysis of permanency planning trends.)
4. **Create a 'Permanency Planning/Promoting Independence Children's Unit' at DADS with responsibility for:**
 - **Developing the expertise and the human resources needed within DADS to address the number of children in Texas institutions**
 - **Reviewing all permanency plans for institutionalized children.**
 - **Acting as a Crisis Team leader when a child is at risk of placement or placed in any facility. Create protocol for crisis team that would consist of DADS staff, MRA permanency planning staff, facility staff, parents/family, and others as appropriate. This team would immediately begin work to assess the needs of the child and work continuously to remove barriers until access to needed community services is achieved.**
 - **Providing technical assistance to MRAs currently responsible for permanency planning for all children in DADS operated or regulated facilities.**
 - **Ensuring that permanency planning includes on-going follow-up activities and is not simply a status report on paper that is filed away until the next 6-month report is due.**
 - **Working to transition all children currently placed in state institutions to less restrictive family-based alternatives.**
5. **Develop a pilot to create emergency living arrangements for children with disabilities needing out-of-home placement. This is to assure adequate time to assess the child and find an appropriate family-based alternative.**

6. **Develop adequate behavioral services, including in-home staffing, to support children coming out of institutions and to help prevent them from going in.**

While less research has been done specific to institutionalized children with intellectual disabilities, there is little doubt among the experts in developmental disabilities that what has been learned with respect to the effects of institutionalization on child development, applies to all children – those with and without disabilities. As stated by Nancy Rosenau, Ph.D., of EveryChild, Inc.,

*We know better--now we have to do better. Children's development won't wait and the system can't afford to use precious resources for the wrong kind of services.*¹⁵

¹ National Research Council and Institute of Medicine (2000) *From Neurons to Neighborhoods: The Science of Early Childhood Development*. Committee on Integrating the Science of Early Childhood Development. Jack P. Shonkoff and Deborah A. Phillips, eds. Board on Children, Youth, and Families, Commission on Behavioral and Social Sciences and Education. Washington, D.C.: National Academy Press

² Ibid., p.3.

³ Ibid., p. 6.

⁴ Ibid., p. 412.

⁵ Ibid., p. 257.

⁶ Ibid., p. 258.

⁷ Ibid., p. 258

⁸ *Healthy People 2010 Objectives for People with Disabilities*, Center for Diseases Control and Prevention, US Department of Health and Human Services. Objectives 6.7a and 6.7b (<http://www.healthypeople.gov/document/html/objectives/06-07.htm>)

⁹ Ibid.

¹⁰ *Healthy People 2010 Progress Review. Disability and Secondary Conditions Focus area 6 Reports and Proceedings: Implementing the Vision Forum*, Atlanta, Georgia. September 20-21, 2002. (<http://www.cdc.gov/ncbddd/dh/hp2010.htm>)

¹¹ Ibid.

¹² Rosenau, N. (2000). Do we Really Mean Families for All Children? Permanency Planning for Children with Developmental Disabilities. Policy Research Brief (University of Minnesota, Institute on Community Integration).

¹³ *Permanency Planning and Family-Based Alternatives Report*. Texas Health and Human Services Commission. Submitted to the Governor and the Texas Legislature January, 2008.

¹⁴ Ibid.

¹⁵ Interview w/ Nancy Rosenau, Ph.D., Executive Director, EveryChild, Inc., April 11th, 2008.

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