

Children's Freedom Initiative

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The Children's Freedom Initiative

Report to the Speaker of the House, Glenn Richardson

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EXECUTIVE SUMMARY

During the past three years the Children's Freedom Initiative (CFI), a coalition of the Governor's Council on Developmental Disabilities, the Georgia Advocacy Office, the Institute on Human Development and Disability at the University of Georgia, the State Independent Living Council and People First, has worked with the Department of Human Resources to make sure that no child in Georgia resides in a state or private institution or nursing home. HR 633, which authorized this Initiative, was passed by the Georgia House of Representatives during the 2005 General Assembly, and the initiative has been reporting annually to the Speaker on our progress. HR 633 will expire at the end of the 2010 Legislative Session.

The Children's Freedom Initiative has worked with the Department of Human Resources to move children from state institutions into permanent, loving homes with the necessary support. We feel that we are near success in this effort and are now seeking to place children in the community who are in other types of congregate facilities such as private Intermediate Care Facilities for persons with Mental Retardation (ICF-MRs) and nursing homes.

During the past three years, the Initiative has learned a great deal about the process of successfully transitioning children back to loving homes; finding, creating and developing the necessary supports; encouraging agencies and providers to work together and share resources and expertise; and creating accountability at the State level. It is time to extend the effort and to work with both the Department of Human Resources and the Department of Community Health to ensure that within the next five years no person with developmental disabilities under the age of 22 lives in a state institution or nursing home.

During this five year period agencies will build the capacity within communities to ensure that all children with developmental disabilities move safely and permanently to homes in the community with their birth families, or with host families if their birth family is not capable of providing care.

Recommendations for the next five years are enumerated at the end of this paper.

CHILDREN'S FREEDOM INITIATIVE: A HISTORY

The Children's Freedom Initiative is a collaborative effort of the Georgia Advocacy Office (GAO), the Governor's Council on Developmental Disabilities (GCDD), the Institute on Human Development and Disability (IHDD), the State Independent Living Council, and People First of Georgia. The mission of the Initiative is to prevent children from going into residential facilities and to ensure permanent, loving homes for all children currently residing in congregate facilities.

The Initiative was launched when the Georgia Advocacy Office obtained from the Department of Community Health a list of 144 children under the age of 22 living in nursing homes, state hospitals, private hospitals and other congregate facilities throughout the state. Since that list was released, we have learned that there are additional children in the custody of the Division of Family and Children Services (DFCS) who are living in hospital units because the agency has been unable to secure adequate care in the community for the children. We know that there may be additional children in other public or private hospitals throughout the state. We also know that over the years, children have been sent out of state by their parents because they have been unable to secure adequate support to care for their children at home.

A key element of the Initiative was the development and passage of House Resolution 633 during the 2005 legislative session. HR 633 urges the Department of Human Resources (DHR), the Department of Community Health (DCH), the Department of Education (DOE), the Department of Labor (DOL), and the Department of Juvenile Justice (DJJ) to work together on a comprehensive plan to identify, assess, and plan appropriate community supports to return the children currently residing in institutions to the community. It requires the agencies to submit an annual progress report to the Speaker of the House and requires the agencies to develop a budget proposal for the 2008 fiscal year. A final provision of HR 633 is the establishment of an oversight committee, consisting of members of the House, representatives from GAO, IHDD, and GCDD, as well as other members, of which at least 60% are people with disabilities and/or their family members.

State agencies have committed financial resources to the Initiative to facilitate the planning process involved in transitioning institutionalized children into the community. Steps in the planning process included hiring national consultants who have successfully moved children into permanent homes in other states, and meeting on a regular basis with a steering committee and the HR 633 Oversight Committee to review the work in progress, make recommendations, address administrative and budgetary challenges, and keep stakeholders informed.

PROGRAM SUCCESSES

In the past three years the Initiative has seen successes. Success is measured in:

- Numbers of children moving out of institutions
- Children who are not entering institutions, and

- Systemic changes that will create a community-based system of support.

The impact of the Initiative extends far beyond the children moving out this year. We are identifying other children living in facilities and are working to move these children into the community.

Additionally, we have deflected the institutionalization of a number of other children with the support of our partners in this effort. Agencies such as the GAO and the GCDD have successfully moved children back into their communities by calling on components of HR 633.

In fiscal year 2007, children residing in state hospitals transitioned to the community with funds made available within the 1,500 Medicaid waiver services appropriated by the 2006 General Assembly. This does not include the number of children who are in nursing homes. Georgia is the only state in the nation to increase the number of children placed in nursing homes. DCH, not DHR, oversees children in nursing homes. The Steering Committee has not been able to get a reliable current count of children in nursing homes from the Department of Community Health.

MHDDAD reports the following progress, as of June 2008:

- There were 50 children on the original list
- 26 children have transitioned into homes in the community
- 13 of the remaining children have an identified provider
- One child is very medically unstable and his/her condition will be reviewed by Dr. Karen Green McGowen in 90 days
- 4 children have no provider identified
- 2 children are encountering issues regarding legal release from the parents
- 4 children have passed away

Of the 13 children with providers, seven need (exceptional rate) funding due to their medically complex issues. The Medicaid waivers, as written by the Office of Developmental Disabilities (DD) and approved by the Centers for Medicare and Medicaid Services (CMS) on October 1, 2007, do not allow for exceptional rates. The Office of DD has submitted amendments to the new waiver to accommodate exceptional rates, which have been reviewed by DCH and the DCH board, and have been submitted to CMS for approval, which will occur within 90 days.

HR 633 has influenced how state agencies deliver services to all persons with developmental disabilities, including children. Some of these changes include:

- *The NOW (New Options Waiver) and the Comprehensive Waiver:* Waivers written by the Office of Developmental Disabilities (within DHR) will make services more self directed and flexible to meet the needs of people with developmental disabilities. Through this waiver, new services such as dental care for adults, transportation, community guides, and behavioral support will become available.
- *Planning List Administrators:* Staff have been hired at the Regional Level to provide support coordination to people on the waiting list. These Planning List Administrators help

people in state hospitals to transition to the community. This went into effect on October 1, 2007

- *Money Follows the Person Grant:* Georgia secured funding made available under the Deficit Reduction Act to draw down an enhanced Medicaid match to move a target number of individuals from institutions and nursing homes over the next five years. The number proposed to move back to the community is 1327 individuals.
- *Increase in Provider Capacity:* DHR is encouraging child placement agencies to apply to be Medicaid waiver providers. These agencies, already engaged in foster care placement, are excellent at recruiting families to support children, especially children with more complex medical needs.
- *New standards for host homes:* The Office of Developmental Disabilities is developing new standards for host homes or life sharing situations.
- *Direct Support Professionals training:* The Governor's Council on Developmental Disabilities has implemented a certificate program for Direct Support Professionals in technical colleges. This program offers both classroom and practical experience for students learning to support people with disabilities in the community. One hundred and eight direct support professionals have completed the 250-hour certificate program.

LIVES OF CHILDREN

The most compelling evidence of the success of the project, and the most profound argument for continuing the effort exists in the stories of children who have moved back in with families and are thriving. Here are some **examples** of children who have moved from state hospitals to communities with natural or host families:

- S.R. moved out of a private ICF/MR with the help of a Medicaid program, SOURCE. She now lives with her mother and attends her neighborhood school. She has been reunited with her extended family that she had not seen in years. SOURCE provides S.R. with an attendant in the afternoons when she returns from school, as well as on some weekend days. SOURCE also provides her with meals.
- D.F. moved out of a nursing home into his mother's home with the help of SOURCE. He has eight hours of nursing care each day. He plays with the kids in his neighborhood daily, has visitors in his home, and recently went camping with his family.
- S.J. moved out of Central State Hospital into a loving host home in Decatur. She volunteers at her local independent living center, is taking classes to earn her GED, and is in the process of finding competitive employment in her community.
- GAO advocates were able to deflect institutionalization of S.M. He has moved into a host home, where he is thriving.
- The CEO of a child and adolescent psychiatric hospital is committed to finding a way to

increase the competence of DFACS workers, as well as her own staff, to create loving homes for 11 children who have resided in the hospital for a number of years. The CFI is providing her with technical assistance regarding this project.

CHALLENGES AND BARRIERS

As with any significant systems change effort, The Children's Freedom Initiative has faced a number of challenges.

- One major challenge is to get the word out to convince people that institutionalization is an outdated, unnecessary, expensive and harmful way to care for children with disabilities. As with any new concept, people have expressed resistance. However, we have found that once we have had the opportunity to educate people, they have been very receptive to, interested in, and supportive of the effort.
- A second challenge has been building capacity for a provider system that supports families. Provider capacity is crucial to ensuring the successful transition of children to safe, loving homes. With the DHR, we are identifying those providers who have competently served children, as well as those providers who embrace the person centered approach to providing services. Many have already begun serving children throughout the state.
- Another challenge is oversight of the transition to community-based services. Once a child has transitioned to a host family, there is still need for family and individual support. Training for support personnel is in process.
- Locating foster or shared family settings that do not interfere with local zoning ordinances that prohibit multiple unrelated people from living together has been a concern for family foster care, or for unrelated people with developmental disabilities who choose to live together after they reach the age of majority.
- In addition, there is the challenge of funding. Currently, one in five dollars supports people in nursing homes. This money provides room and board but does not provide services to the person with disabilities. Home and Community Based Services funding provides services but not room and board. Some children will need additional funds to cover transitioning, extra pharmacy and behavioral services.

RECOMMENDATIONS

The Children's Freedom Initiative is an ongoing project that will span many years. The Oversight Committee makes the following recommendations:

- Consider legislation, or a request to the Governor for an Executive Order, mandating an end to the institutionalization of children under the age of 22.
- Request that Speaker Richardson ask DHR and DCH to conduct a new census of children under the age of 22 living in institutional facilities, including, but not limited to pediatric

hospitals, nursing facilities, Skilled Nursing Facilities, Intermediate Care Facilities (IFC-MRs), group homes, or any other congregate setting paid for with government funds.

- Review the membership of the Oversight Committee appointed to oversee the transition of all children leaving facilities, and recommend new appointments as necessary.
- Designate funding to transition children living in facilities other than state hospitals to their community.
- Continue development of appropriate community supports for children leaving hospitals and for families who wish to keep their children at home.