

# Promising Practice Brief



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## Children's Freedom Initiative

The CFI was formed in the winter of 2004, through a partnership between the Institute on Human Development and Disability (IHDD), the Governor's Council on Developmental Disabilities (GCDD), and Georgia's protection and advocacy entity, The Georgia Advocacy Office (GAO). The DD Network partners were soon joined by People First of Georgia and the Statewide Independent Living Council. More recently, the new Georgia UCEDD, the Center on Leadership in Disability (CDL), joined the initiative. CDL brings expertise in positive behavior supports, enriching the work of the initiative. The mission of CFI is "to make sure that all children now residing in congregate facilities are supported to live with permanent loving families and that in the future no child will be institutionalized." IHDD's research findings that children who were placed in institutions were placed by families who lacked necessary supports to care for them at home, reinforced the development and initiatives of the Children's Freedom Initiative (CFI).

DD Network partners collaborated in sponsoring "The Children's Freedom Initiative: A Summit for Change" in 2005, where a variety of stakeholders learned how other states developed family support systems for children with disabilities, and also presented the CFI at the Alliance for Full Participation conference in 2005.

Network collaboration continued with lengthy meetings resulting in the development of proposed legislation, which was subsequently passed by the Georgia State Assembly (H.R. 633) in 2005. This legislation urged Georgia's Department of Human Resources, Department of Community Health, Department of Education, Department of Labor, and Department of Juvenile Justice to coordinate the development a plan to provide home and community based services to children with developmental disabilities under age 22, with the goal of fully implementing the plan within five years. This legislation also created an Oversight Committee for Planning to Provide Home and Community Based Services to assist in developing and overseeing implementation of the plan. This Oversight Committee includes representation from the three original partners in the DD Network, in addition to individuals with disabilities and family members, and members of the House of Representatives. The 5-year plan was received and reviewed in 2006, and members of CFI's Steering Committee (consisting of directors and staff of all four DD Network partners) meets monthly with the State DD

Director to support the planning process.

IHDD completed a survey of all nursing homes in Georgia to determine the number of children living in such settings. These findings provide important information to support efforts to obtain increased Medicaid waiver funding, as well as the development of policies that will prevent children from being institutionalized in the future.

In the 2006 legislative session, Medicaid match funds were appropriated for all 44 of the children living in state institutions. Planning and implementation of transitions for these children has been slow, but all children should move to family homes by the end of 2009. The next, more difficult step, is to work toward transitioning the children currently living in private nursing homes. After that work is completed, CFI will focus on children and youth living in private residential facilities, an even more difficult task.

Additional areas of collaboration between the DD network partners related to the CFI include undertaking a media campaign consisting of print publications and video development and dissemination to further the reach of individual and family stories, and findings of the CFI project. IHDD developed and produced two publications to support CFI: *From Loving Arms* (A book of stories from families whose children are or were institutionalized) and *Parent Journeys* (This publication couples facts about transition from institutionalization with advice from parents and care givers who have participated in the deinstitutionalization of their child). These publications are available on the IHDD website.

One of IHDD's key roles in this collaborative effort is their expertise in research. Just as IHDD's research provided the data about lack of family supports that supported the development of CFI, they will continue with longitudinal research over five years as the children transition from institutionalization into family life. This data, along with the personal stories of those involved, will be shared with legislators, policy makers, and the media in order to garner more support for the initiative.

## Why is the Children's Freedom Initiative a Promising Practice?

Children's Freedom Initiative (CFI) was identified as promising in the MTARS evaluation for its collaboration with DD Network partners and self-advocacy groups in locating the children under age 22 who were institutionalized in hospitals, nursing homes, and other private facilities in the State; proposing legislation to the State Assembly requesting State agencies work together to transition every institutionalized child to a family home; overseeing transition planning; sharing the personal stories of institutionalized children and their families; securing State Medicaid match waiver funding for all institutionalized children; and undertaking longitudinal research studies to document the lives of institutionalized children before and after their move into family life. Children's Freedom Initiative was identified as promising during the 2007 MTARS Reviews.

## Suggestions for Replicability

The Institute on Human Development and Disability offers these suggestions for implementing similar collaborative efforts:

- Identify an issue of shared passion among network partners, and undertake focused brainstorming and problem-solving efforts to develop a plan to address the issue. Maintain an attitude of, "This is needed; we can do it."
- Make a commitment to continue working on the issue even when barriers appear to be insurmountable. In the CFI, early successes were followed by budgetary setbacks and slowed progress. The ADD network partners are determined to overcome these obstacles and to continue to work on the initiative until the

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goal has been achieved.

- Address all aspects of the policy issue. For CFI, it is very important to “close the back door” to residential placements by insuring that family and community supports are available. If a child moves into an institution or nursing home every time a child moves out, the goals of the initiative will never be achieved.
- All ADD network partners are contributing to the funding of CFI. One partner is not responsible for financing the work of the other partners. This has created joint ownership in which all partners have an equal voice at the table and have a financial investment in the success of the initiative.
- At the beginning of the initiative, the ADD network partners decided to hire a skilled facilitator who has stayed with the project. She keeps momentum going when things slow down, organizes and facilitates CFI meetings, helps set objectives and timelines, and tracks progress on outcomes. Having a dedicated person responsible for these tasks has increased our success.
- Involve UCEDD trainees. From Loving Arms was researched and written by an IHDD graduate level trainee who is now an employee of the Georgia Advocacy Office.
- The most powerful stories about the destructiveness of institutional life are told by self advocates. The testimony before a committee of the Georgia legislature by an IHDD staff member who grew up in an institution was extremely persuasive in changing beliefs and attitudes.
- Build on the gifts of the ADD network partners. Each program is different and has unique strengths and capacities. Each program also has limitations. Have open discussions about what each program can, and cannot, do.
- Celebrate small successes. The work of changing political systems is difficult and success sometimes comes in small steps. One changed life is cause for celebration. Seeing one child enjoying family life provides motivation to keep working until all children live in loving families.

## For More Information

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