

# CHILDREN'S FREEDOM INITIATIVE'S RECOGNIZED ADVOCATES:

Seated (l to r): Mathew Harp and Callie Moore. Standing (l to r) Brenda Parker, Zenobia Willis, Pam Walley, Karl Lehman, Sally Carter, Jim Schnupp, Greg Schnupp, Bobbie Davidson, Former Rep. Judy Manning, Katie Chandler, Dottie Adams. Not present: Beth English, Pat Nobbie, Joe Shapiro and Gwen Skinner.



The following advocates were recognized at the CFI 10th anniversary event for their work in moving children out of facilities and into inclusive communities.

- **Sally Carter** and **Bobbie Davidson**
- **Beth English**, executive director of Easter Seals Southern Georgia
- **Mathew Harp** and **Zenobia Willis**
- **Karl Lehman**, president and CEO of Childkind, Inc.
- Former State Rep. **Judy Manning** (R – District 32)
- **Pat Nobbie, PhD**, program specialist at the Administration for Community Living
- **Brenda Parker**
- **Greg, Jeannette** and **Jim Schnupp**
- **Joe Shapiro**, investigation correspondent for National Public Radio
- **Gwen Skinner**
- **Pam Walley** and **Callie Moore**

## Alternative Solutions

A challenge in Georgia has also been in finding people who are interested in opening up their homes to kids as foster models.

Nancy Rosenau, executive director of EveryChild, Inc. located in Austin, TX noted the similarities between Georgia and Texas' attempts to remove children from these settings.

"The majority of the children who we have helped move from facilities have NOT returned to their own homes," said Rosenau. "They have moved in with families in the community who have opened their homes to them and we have found that has been a necessity in order to create family life."

EveryChild started similar work like CFI in 2002. Since then, leaders and advocates throughout Texas worked to bring 955 children out of nursing homes and currently have 318 left to move into the community.

"People are very surprised that we have a need for foster homes in general. I think we've not done a good job, as government, in relating the need to the community because what we're finding is when we relate the need, people step forward," Cagle remarked about the need for foster homes in Georgia.

But, depending on the service system isn't enough.

Zolinda Stoneman, director of the Institute on Human Development and Disability at the University of Georgia noted that it is important to engage the communities.

"We really need to figure out ways of engaging all those people who are shocked to learn that there are kids living in nursing homes," said Stoneman. "There are families who right now would be more than willing to talk about potentially supporting a child and their family. But they don't have any notion that there are kids out there who really could use and need them."

**But, depending on the service system isn't enough.**

The State of Texas passed permanency legislation that provided alternative solutions such as adoption or foster care rather than congregate care. For Georgia, CFI and its band of collaborative organizations would have to explore how to take congregate care off the table.

"If we know that what it really takes to keep kids – keep anybody, not just kids, not just people with disabilities, but anybody – safe, is to have neighbors, friends and loved ones around you, then it is about going into a community and saying 'how do we bring people together?' " said Eric Jacobson, Georgia Council on Developmental Disabilities (GCDD) executive director.

But to provide quality care in the community means that the State must plan to improve the quality of support, including workforce development, ensuring that support workers are paid a living wage, reducing staff turnover



and addressing those concerns in the State. It also means that the State needs to start building regularly scheduled respite care into the treatment planning process so families don't burn out.

"How do we support families, through the community, to support their kids and not necessarily through the Medicaid program or [Early and Periodic Screening, Diagnostic and Treatment]?" added Jacobson. "We know that there will never be enough financial resources – even in a State where the economy is growing – that will be available to take care of everybody, and if we don't figure out the community aspect of it I think we're going to be lost."

## The Commitment

Although there was a lot of discussion in terms of getting those 41 children out of skilled nursing facilities or private institutions – both in political commitment and acknowledgement of barriers – state agency leaders provided stark realities of when they will be out of these settings.

"I was asked to come and talk about whether or not I could commit on the behalf of the State to say that there never would be another child admitted to a nursing facility. I was clear then, and I have to say now that I don't believe I could commit to that. Not because I don't agree with it, but I don't think I'm in a position to say that there will never be a circumstance where it would not happen," said Reese.

Berry also added that the State recognizes the urgency. "Lieutenant Governor [Casey Cagle] states that this is a top priority," he said. "We're in agreement. But I am not going to set a deadline from our department's standpoint."

Even though the commissioners couldn't provide specific details on moving the children, advocates spoke about what they can do to hopefully move the process along.

"We don't want to wait around if the Commissioners, for example, want to have a moment of admiring the problem and not quite jumping into the urgency and action we are hoping for," said Ruby Moore,

executive director of the Georgia Advocacy Office. "I don't want to put all of our eggs in one basket and say 'unless we can get them to do that we can't move forward' because there is always something that we can do."

"I think that there is a commitment to get them out."

Along with legislative support, community engagement is becoming the central key to continuing advocacy for removing the 41 children out of these facilities.

"I think that there is a commitment to get them out. It may not be by the end of the year, it might not be – as one legislator wanted – by the time school begins in the fall, but I think that there is support both on the legislative, bureaucratic as well as the advocacy side, to figure this thing out and get those kids moved out," Jacobson added.

I think the greater question is how do we shut that front door, lock it, and make sure it never opens again? And that's the tough part."



Advocate Mathew Harp attended the Children's Freedom Initiative's anniversary celebration in Atlanta this past spring.

During CFI's celebration and call to action event, Brittany Curry covered the back wall with graphic depictions of the comments and opinions expressed by the attendees and speakers.



This is a

## MERITORIOUS EFFORT

that we can and  
should be working on,

## AND WE ARE.

# The Fight for 41 Children

By Devika Rao

In April, disability community leaders, people with disabilities, parents, caregivers and citizens gathered together to seek answers to a very important question – why has it been so hard to move the remaining 41 children with disabilities living in skilled nursing facilities and private institutions into integrated and inclusive communities?

They came together at the Atlanta Community Food Bank for the Children's Freedom Initiative: A 10-Year Celebration and Call to Action event honoring the coalition's work over 10 years, but also to remind everyone that there is still more work to be done – specifically for those 41 children who are in these facilities.

Since 2005, the Children's Freedom Initiative (CFI), disability rights advocates and state agencies have worked hard to move all 144 children living in private facilities back into communities where they are able to thrive.

Sharon Lewis, principal deputy administrator of the Administration for Community Living and senior advisor to the Health and Human Services Secretary on Disability Policy, addressed the fundamental concept of community living in her keynote speech.

"Social isolation is twice as deadly as obesity, and the most vulnerable are children," said Lewis. "And we know Georgia has every opportunity to become a zero state with no children living in institutional facilities."

To address this possibility, a number of state agency leaders served on an expert panel to discuss moving these children into the community through legislative means. They included Georgia Department of Community Health Commissioner Clyde Reese, Georgia Division of Family and Children Services Director Bobby Cagle, Georgia Department of Behavioral Health and Developmental Disabilities (DBHDD) Commissioner Frank Berry and Kim Grier, adult guardianship

specialist at the Division of Aging in the Department of Human Services.

Across the board, there was sound agreement from the community to the state agencies that children should not be in skilled nursing facilities or private institutions.

**"Georgia has every opportunity to become a zero state with no children living in institutional facilities."**

"I can say unequivocally that every time the subject of children in nursing homes has been broached with me, I have been clear and I absolutely agree there should not be children in nursing homes," Reese said. "I believe this is a worthwhile objective. This is a meritorious effort that we can and should be working on, and we are."

### The Challenge

In 2010, Georgia was sued by the Department of Justice, and at the time, the State signed the most comprehensive settlement agreement in the country. The requirement was to transition all individuals who were in state institutions into a community-based setting by the end of June 2015. (*Read more about the Department of Justice Settlement on page 18.*)

The settlement agreement was a five year plan that stipulated that the State will move 150 people each year for the first four years,

"Social isolation is twice as deadly as obesity, and the most vulnerable are children"



and “all remaining” by the fifth year into integrated and inclusive communities.

The agreement was to bring the State in compliance with the 1999 US Supreme Court ruling of *Olmstead vs L.C.*, which mandated that states eliminate unnecessary segregation of persons with disabilities and to ensure that they receive services in the most integrated setting appropriate to their needs.

However, during the transitions, independent reviewers brought photos of unlivable conditions such as rat poison or antifreeze underneath the stoves and broken glass on porches. As a result, “I stopped transitions,” said Berry.

Berry’s purpose was to ensure that, “when we move someone back home, into the community, we can look family members in the eye and say that it will be a place that people *want* to call their home.”

The transitions have met with two distinct challenges keeping the State from accomplishing this goal.

“One, it’s the quality of care that individuals get in the community. And the second one is the oversight that our department provides for that quality of care,” he added.

## Family Support

National Core Indicator data shows the quality of life for an individual who is living in a relationship-based circumstance – whether it’s with family, roommate or someone of their choosing – is healthier and happier in the long run.

**Families cannot  
do this alone.**

While the evidence on living in nurturing, inclusive communities points to positive impacts, “families cannot do this alone,” Lewis said. “We know that if families are not adequately supported, that’s a problem.”

As a result, a lot of children are being put at risk of institutionalization and other bad outcomes because they are not getting the proper support they need.



Deputy Administrator Sharon Lewis, keynote speaker, stands with members of one of the expert panels (l to r): Adult Guardianship Specialist Kim Grier, Commissioner Frank Berry, Commissioner Clyde Reese and Director Bobby Cagle.

There is \$450 billion of unpaid caregiving provided by families across this country. Although Medicaid is the big funder for waivers for people with disabilities, long-term supports and services have not been addressed and it’s a critical issue, according to Lewis.

“Huge benefits have come for people such as Medicaid covering diapers and other things like nursing support,” Pam Walley, a parent advocate, said while applauding the changes that have come through Medicaid. “But, what is really missing is the supports to keep the kids out of the facilities. It comes back to long-term care support because as the kids get older, so do the parents and it becomes harder to keep up.”

Walley and her daughter, Callie Moore, have been advocates for moving children out of skilled nursing facilities or private institutions since 2005 and were recognized for their advocacy work at the event. *(Please see sidebar on page 10 for the complete list of recognized advocates.)*

The demand for waivers will also increase in the coming years due to the aging population – including parents of children with disabilities.

In addition, there is a dire need for professional in-home care or nursing supports. Metropolitan cities like Atlanta provide access and availability to care, but the trouble has been in rural Georgia where DBHDD has had a difficult time recruiting and retaining high quality staff or caregivers.

**The Children's Freedom Initiative is a coalition of disability organizations involving Georgia State University Center for Leadership and Disability, Georgia Advocacy Office, Georgia Council on Developmental Disabilities, the Institute on Human Development and Disability at the University of Georgia, People First of Georgia, and the Statewide Independent Living Council of Georgia.**