

Unlock the Doors to Real Communities

Listening Tour- Macon



Arc of Macon

Again, a different type of gathering. An older couple who have a son who lives in his own apartment. A retired couple who have just received their license for a community living arrangement and want to support some individuals moving out of Atlanta Regional. A mom taking care of her thirty one year old son with significant disabilities. Staff from the State office of DD. And our hosts, staff from the Arc of Macon.

So the Mom with the thirty-one year old son is the story I want to focus on. She moved here four months ago from South Carolina, to be closer to her daughter who lives in Warner Robbins. She had a waiver for her son in South Carolina. He is extremely medically fragile, having incurred a brain injury due to lack of oxygen at the age of 13. The convoluted details of her situation I will not be able to responsibly report. The bottom line is that she couldn't get enough support for his nursing needs in any of the existing programs in Georgia, CCSP, SOURCE, and when she couldn't continue the care herself and realized she was going to be put on a waiting list, she put him in a nursing home for 90 days so he would qualify for the Money Follows Person program.

Here is a sobering comparison. For the past 8 years, this mom cared for her son at home with support provided through waivers, in two different states, and he never once entered the hospital.

In Georgia, he was home for three months, and his Mom had no support. He has been in a nursing home for one month and has been hospitalized three times for infections and skin sores. Actually, he has only been IN the nursing home for nine of the last 30 days, and the rest of the time he has been in the hospital. Im sure this is not cost efficient, and it is certainly not good care. She asks, Why is Georgia so backward?

Here's another sobering contrast. On our way back from Ocilla on Wednesday, my Unlock partner shared with me a few pages from the Georgia Health Care Association's (read Nursing Home Association) Legislative Call to Action, entitled, "Truth, Knowledge and Understanding: Opening Hearts and Minds," in which they instruct the nursing facility staff who are to host legislators "to show them your frail and sick Medicaid patients" and worse, "Let them know that campaign contributions will be available to them when they visit."

Maybe the Georgia Health Care Association would be interested in introducing her son to the local legislators as one of the frail and sick Medicaid patients they so want them to meet. You know, to "humanize" (another word from their material) the campaign to open hearts and minds.

Heartbreaking.

Now to switch topics. This conversation about unmet needs led to a conversation about advocacy. There was a woman there who works for one of the provider organizations, who is also a mom and she runs the family support program. She recalled how back in the day the parents of the Arc were thousands strong, came up to Atlanta in buses and took over two or three motels. Legislators would not make a move regarding people with disabilities without asking the Arcs opinion. She cannot get parents to advocate like that now.

So what changed? I wanted to know. We all thought about that for a moment. The structure of families has changed. In the Arc's heyday, there were more intact nuclear families. This mom's husband worked full time, and that enabled her to be the advocate, go to meetings, travel to Atlanta and meet with legislators. Another member of the group said, "We are reactive now, not proactive." "We are overwhelmed," said another member of our group. Families are struggling to keep the roof over their heads. They have lost jobs in the economic downturn or else have quit them to stay home to care for their kids once they got out of school. They are trying to keep a home, food on the table and give care 24/7. Who has time for advocacy? "They have been waiting too long," another offered. They know there are 6,000 people on the list. They have been waiting for years. There's no hope. People need hope if they are going to step out and advocate. They have to feel like something is going to change.

They questioned the point of Disability Day at the Capitol. Too many people, its too uncomfortable for them, the lines, the wait, the weather, trying to get around, to eat....And no one can see their legislators. It's too busy and hard to get that many people around the Capitol. Maybe we need to go back to regional days at the Capitol. A couple busloads at a time. Disability Day is a show of strength. But what are we doing with that after the day is done?

It is telling that despite personal invitations by the hosts of each of these events, and individual invitations from me, not a single legislator has attended these gatherings. A couple of our loyal supporters in the legislature called to express their regrets. But we have to wonder, to whom do they feel accountable? All advocates know that there are competing interests, that legislators get bombarded, that there are only so many resources to go around.....the conversations about the needs of the disability community are actually conversations about much bigger issues about all citizens and their relationship to government. Can citizens use the power of the vote to change the political support for these issues? Are the alternative candidates available? We've had discussions about critical mass. A coalition of disability advocates. Getting a movement.....What do we do next to move the conversation from "6,000 people are on the waiting list?"

Thought-provoking. These visits have been extremely thought-provoking. Please share your thoughts on how to strengthen this movement.

Patricia D. Nobbie, PhD
Deputy Director
Georgia Council on Developmental Disabilities