

Unlock the Doors to Real Communities

Listening Tour- Bleckley

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The Arc of Bleckley County Georgia, September 26th
New Life Church of God
93.5 degrees hot!
30 attendees
Transportation Referendum Straw Poll: 10 yes 1 No.

This was the first of Unlock's Listening tours, and a test drive of the new agenda; bring good southern cooking for potluck, make sure everyone signs the Get Connected sheets, gets a name tag, meets and greets. Spend a little time sharing information on the budget, the Department of Justice Settlement Agreement, the Transportation referendum, Olmstead, the waiting lists. Then ask, "What's working for you and your family?" What are two things that would make your life even better?" What's one thing that was really frustrating for you and your family this year?"

The discussions and the answers began to blur together, but we heard plenty, and some very common themes. First, family is a critical foundation for everything. In the gathering, there were several single parents of adults with disabilities, one older couple caring for 3 adult brothers with autism, grandparents raising grandkids, an aunt raising her nephew, and even a couple of neighbors who took in their friend's son when his Mom passed away. Many of the individuals these folks were caring for had lived in nursing homes, Gracewood, Central State for periods of time, but their family members brought them home because they didn't like how they were being cared for in those places. But they are the sole support now, except for the time they spend in day services, so a recurring question was, what will happen to my son, nephew, granddaughter, when I die?

What would make life better? Respite. Some families had it, some had it in spades, and some had nothing. One single Dad had a couple hours off twice a week, and some Saturdays from 9 to 4. He kept saying, "I don't have a life." But leaving his son with someone who didn't know him well worried him more than not having a life. Providers didn't seem to be able to provide respite cost effectively unless they had several individuals at a time, and families wanted individual attention. Somehow we need to get more creative about this.

Which leads to another theme. There is frustration on all sides. Providers feel there is too much red tape. Too many forms, too much information required that is duplicative and not relevant to the request. Families feel providers and staff don't listen, don't respect their advice when it came to their own kin. They feel staff wasn't paid well enough to survive in the field, even though they care about the work they do.

Families seemed to do well if they had some support. Someone to come in the afternoon to help with independent living skills. Someone to bath and help groom and dress, help their family member do house chores. They wondered why it was always so hard, why they had to beg for support, “beg on our hands and knees” for what they need for these folks they love and care for, when other ‘typical’ children’s parents didn’t need to beg.

Several individuals also talked about the disconnect between the school system, teachers, and what folks need as adults. Teachers don’t know, they said, what’s available. A teenager who was present and quite active in her school, and with definite employment goals, wonders if she will get support to meet them.

Parents also want help with life planning. Wills and trusts. Access to lawyers who can help. Guidance on what to set up. They are worried about who will care for and about the individuals they have loved and supported.

It’s something I’ve written about before. The state could never replace the care that these folks have provided for people their whole lives, usually at great sacrifice. What I asked, and will continue to ask in the next tours, is the question, “How can we support these communities to care for the people they love, honoring and respecting their relationships, not ignoring their wishes, but ADDING to their capacity, so all the people in the family home can have a good life?”

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