

Unlock The Doors To Real Communities

Listening Tour- Lyons

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Every one of these events is different. The Listening Tour in Lyons was more like a kitchen table conversation. Four attendees and three of us, we put two tables together, got plates of roasted chicken, shepherd's pie, salad and sweet tea, and ate dinner together. Four of the seven of us were parents of adults with disabilities. I started by sharing my planned information on the GCDD, who we are, what we do, and then talked about why we need to build and continue relationships with the local Arcs because we need the critical mass of family voices to share stories. But very soon we settled into more of a "family" conversation. At one point, the President of the local Arc asked us, "What did they talk about in Bleckley last night? Because I want to be able to share with my Arc folks the important information." And I said, "You know, the same things they were concerned about, are the things you are talking about here."

Family mattered. The parents there had cared for their sons and daughters for decades. The provider in the group was frustrated with the reduction in funding, the complication and segmentation of the waivers, and wondered why she couldn't hold on to vacated waivers for her families that she knows needs them, but instead must give them up, maybe to another region. I shared what a Planning List Administrator in the metro area told me when I called to check after a waiver for what I considered an urgent situation.....she had 10 waivers for 999 people in her region. So "urgent" becomes somewhat relative. The provider also felt strongly that youth graduating from high school should be supported to get jobs right out of school. If not, they go home and their parents get used to their SSI check contributing to the family income and it's much harder to move them out once everyone gets comfortable with that arrangement. At this point, the high school calls the service center director in for the IEP meeting in the senior year, and wants to fill out the paperwork to send the youth to the center right from high school. The parents have to work, they can't afford support at home, so that's the option. But the director doesn't think this is good, she thinks they need another option when they get out of school.

The older parents were clearly conflicted about employment. They really didn't think their son or daughter could work. They already provided so much support, filled out so many forms for money, SSA, etc, they didn't think employment would make that big of a difference or that the benefits would outweigh the concerns. But they understood how younger parents raising children today would have expectations of employment, how work was a foundational life experience that most people expect to participate in, and they supported figuring out how to get young people to work before they lapsed into inactivity at home.

There is really a lot of concern, and a real lack of knowledge and information about life planning, who would care about their children when they were gone. There was a shared intent among us that we didn't want to expect other siblings to provide support after parents, that we hoped we would be able to establish something that would allow siblings to have their own life. But then what? If there are no other close family, no good friends or neighbors, what do you plan for? One of the moms, nearly 80, said when she and her children got together, at their request to plan for their sister, all she could do was cry. They didn't get beyond that. But she needs to meet again and again and get something established, so no one will be surprised. She'll feel better, they all will feel better, once there is a plan.

Like I said in last night's blog, somehow we have to figure out how to build the capacity of communities to take care of their own. Because more than likely, the jobs for folks come from relationships in the community, and the sentiment around out table was that they don't necessarily want to rely on government support, but they don't want government to get in their way either. We need to work on building the capacity for youth to graduate and work, and we need to design supports for people to stay in their communities, beyond their parents' lives.

And then we had home-churned chocolate ice cream, we pulled out smart phones and shared pictures of our kids, I got complimented on knowing how to carve a chicken, and we cleaned up together, hugged and departed.

Next week, Quitman, Fitzgerald and Macon.

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