

Unlock the Doors to Real Communities

Listening Tour – Summerville, near Rome, GA

Summerville, near Rome Georgia
Arc of Chattooga County, Host
October 19, 2011
47 attendees



The last time we were up in this neck of the woods for a conversation with this Arc, it was winter and Dave and I drove up and back in the dark. I remember it was a dark, lonely ride, and it seemed to take forever. This time, we left in the afternoon, it was different time of year, and we enjoyed a scenic, pretty drive with the trees turning colors. Rep. Barbara Reese arrived from another direction, after coming through a rain storm which was followed by a beautiful rainbow, she said.

The Arc volunteers had laid out quite a spread of food, set tables with fall colors, pumpkins and leaves and families sat together at tables of 6 to 8 filling the room. The sole county commissioner also showed up, and a former mayor. There were also a number of individuals there who have created recreational and social programs for people with disabilities, by the skin of their teeth because of a total lack of services. Dave and I shared the usual information on the settlement agreement, which will be a year old today on October 19th, as well as information on MFP, Olmstead, the Home [Access](#) Legislation and the Individual Development Account legislation. And then I opened it up for discussion. I wanted to let the tables hold their own conversations and then share, in response to our target questions like, What's working? What's not working? And a couple of others. But right away, it became apparent that people needed to share their needs.

It was the first meeting where we had several family members cry. A sister started talking about her brother who had graduated from high school, and who wanted to work but was just home, with nothing to do. They had called legislators, and their local elected officials, and been to providers, private schools and explored every option they could think of, unrelenting, and had come up with nothing they could access or afford, and she was crying with frustration. Another parent sat next to her and angrily confirmed everything she said. She was a single mom. She had no family, "I've lost everyone," she said, "I'm all he's got, what will happen to him if something happens to me? What's the point of education and of all the years in high school if you are just going to let them out to rot?" At that choice of words, you could see several people in the room cringe, including me, but I couldn't refute how she felt. Another parent used the word "disintegrate. He's disintegrating." A local businessman, out of the goodness of his heart, gave this young man, her son, a job one day a week for 2 hours. He wants to work more.

At that point, I lost the structure of my agenda, but so it goes. The point is to hear people, whatever they have to say. I felt helpless because I know they are telling the truth about their lives, and how much they care about their family members, and how much it hurts, but it is hard to listen without having a solution. It's also difficult knowing how hard we are working on transition, on employment, on resources to address the waiting list and nothing appears to be shaking loose in these communities.

Another thing they mentioned is how hard it is to connect with each other, to share information or get information. There are some resources, some levels of networking and ingenuity and natural supports that exists in each of these smaller communities, but they need ways to connect to each other.

And then there is the other end of the spectrum. A sister of an older woman with disabilities, their parents whom she had lived with recently passed on, and the family struggles to figure out a way to support their sister in the life that she wants. The sister providing care has a family leave of absence that enabled her to stay home during this transition but it will expire in 4 weeks. Then what? What will they do? She has no idea.

Again, I strongly believe there are dots to connect. There are accessible homes with no supports funding, but a combination of resources could provide support to someone in that home. There are businesses that have work, but no knowledge that there are young people desperate to contribute. There are organizations with a mission, but struggling to keep the doors open. There are grants available, but no technical expertise to assist in writing and implementing a project. There are local elected officials with a heart who don't realize the state is not providing these supports, but have local resources to contribute. There are kids out of school who want to work, but have no support to find jobs, get to them or stay in them successfully.

I wonder about the waiver "box" we have created and the pent-up demand that goes with it. We have advocated for money in the state budget for waivers for 15 years. Families are at the mercy of that list. What if we could get supported employment for a youth just out of high school? We could blend school funding, VR funding, and DBHDD funds and get someone in a productive day? That might cost \$10,000, maybe less. Jail and nursing homes cost much more. What if we could help communities create co-ops with some of that braided funding? What if we could hire

a community member to coordinate, keep their ear to the ground about opportunities, make introductions to businesses and find the providers. Such a little bit of resources would knit these common interests together. It is what we heard in other communities. “I just need some help, some tools, something to leverage to keep these kids off the streets, in volunteer jobs, with a social life, in a home of her own.”

We have to find a way to break out of the system boxes we created.

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