

Reimagining Families and Support, Pat Nobbie

April 15, 2021

Family Support and Navigation Summit

Good Afternoon everyone and thank you so much for joining! And especially thank you to all the partners who put this summit together for inviting me to share some thoughts on Family Support.

I am going to share what I have learned about family support primarily as a Mom and as an advocate over the years. Each of you as family members and supporters of family have your take. Hopefully, our experiences and knowledge will converge in some ways. In the end, family support is in the eye of the beholder.

All versions of family support start with family stories.

My story started with the birth of my daughter Mia in 1984, in the US Virgin Islands, after an uneventful, full term pregnancy. Her diagnosis of Down syndrome was a surprise, completely unexpected. When my up the hill neighbor Debbie called to congratulate me and I told her the baby had Down syndrome, she paused just a second and then said, “Oh. Well you can handle that.” I can’t tell you how many times over the years I remembered her first words as we faced the challenges of raising Mia.

It also helped enormously that there was a developmental pediatrician in the hospital that night, who had come from NY to train neonatal nurses, and he visited me the next morning before I had even seen Mia again. His first words also stayed with me as a guide throughout her life. He said, “Mrs. Nobbie, I have examined your baby and she is healthy and strong. My advice to you is to take her home and treat her like any other child. She will be the one to make you stop and smell the roses.” He also advised me to give her two years of my undivided attention. So I quit my teaching job and stayed home with her. We were penny-scraping poor, but it was worth it.

My own blood relations had no previous experience with disability. Mia was the first grandchild, so there was the whole adjustment of expectations, the initial grief, questioning, blaming, negotiating that they had to move through. But when my mother visited when Mia was around 8 weeks old and decided she was more like any other baby than she was different, everyone moved on.

In reimagining families, the first question is “Who is family to you?” In my situation, and as I suspect in many of yours, family is made up of the people who extend unconditional love and acceptance to you. They are “your people.” They may or may not be related to you by any “degrees of consanguinity.” They are the ones who show up when you need them, no questions asked.

Being more flexible and creative in constructing our families does fly in the face of social norms and also many laws and regulations that vary widely across states. There are many restrictions placed on who a person with disabilities can give permission to act on their behalf. In voting, in medical care, in handling money or estate planning, there are various and inconsistent rules across states on who a person with disabilities can ask to assist or represent them – or even be with them in the hospital. Granted, these rules are in place to protect them from being taken advantage of – but they are also barriers to individual decision making.

Recently a couple of movements in the community of families experiencing disability has opened up the options for determining who “your people” are. The HCBS settings rule promulgated by CMS in January 2014 reviewed the required elements in the person-centered planning process, one of which was that the person owning the plan had the right to determine who should be invited to that process. This is an opportunity to document who your people are. Last spring, the National Quality Forum, completed a two year-long process to more fully describe these elements of person-centered planning and to issue a white paper intended to provide guidance to individuals and their families, state IDD and BH systems and providers on how to conduct person-centered planning activities. That workgroup, on which I served, was very focused on the self-direction rights and capabilities of people to include who they wanted in the constructed of their plans.

In addition, practice of self-determination and Supported Decision-making also builds some structure around the rights of people to determine who is included in their lives, their homes, their activities and engagements. In the case of Jenny Hatch, who chose friends to support her over family who she felt restricted her, these decisions have legal weight.

People without disabilities can make these choices without much pushback. Recently, a very close lifelong friend of mine asked me to be the executor of her will, in the event her husband is unable to serve. She teaches in a public school system and she was very concerned about her exposure to COVID. She has 7 brothers and sisters. Why me? Because they are all over the country and I know her the best she said. And she can designate me without any question from legal authorities.

Mia has been collecting family her whole life. She has two younger siblings and will acquire a brother-in-law when her sister Annie gets married. Her Dad passed away 6 years ago, but she has Aunts and Uncles and cousins that she maintains contact with. She lives with a family in Athens Georgia, so she has Laura and Joe and their three kids who adore her. This was her choice, to move out of my house. Laura's parents live in their neighborhood, and her sister and her husband and their two kids as well, so Mia also has contact with all of them, and when Laura and Joe need to go out of town, Laura's parents step in. Then she has had the same Direct Support Person since High School, Fabersha, who has two daughters and two grandchildren, a sister, her mother and their extended families, so Mia has all of them in her circle. And then she has been employed at St. Mary's Hospital, in the Short Stay and pre-op Surgery units for the past 9 years, so she has a bevy of nurses in her sphere, who, hilariously, she has ranked in order of BFF status, from 1-21 last time I checked. Each nurse knows her rank, and occasionally they vie to advance but know that Mia is the final arbiter. These work relationships extend outside the hospital. Mia knows their husbands and kids and has been invited to baby showers and birthday parties, and nurse's nights out.

Out of all of these relationships, only two people are paid.

And then she has her own friends, many of them from High School or summer camp that she started attending at the age of 12 when we moved to Georgia. And those young adults and their parents are also people we can count on in an emergency or for fun.

Mia is not just on the receiving end of all these familial connections. She never forgets a birthday. She sends 60 cards at the holidays. She has regular phone calls at night with a small circle of friends. Her siblings call every day. She always asks how other people's families are. She is a great birthday card picker and a great gift giver. She mourns deaths and participates in weddings. She maintains her many family relationships.

Mia is also discriminating in a way that has occasionally puzzled me. Every once in a while, she takes offense to someone whom I would not consider at all offensive. Individuals at church; individuals in the service "system" who should know how to approach the people they serve; teachers. All I can say about this is that I learned to trust her reactions. This was an important lesson for me especially when she was a young adult. As she began wanting to exert more control over her life, I had to learn to stand back and let her lead. Hard to do for any teenagers, but especially for someone about whom society expects you to be more vigilant and protective. I had to create and defend that space for Mia to begin making her own decisions about people while still being aware of her safety. And be willing to be criticized, but not bothered by the criticism. Sometimes that was an opportunity for me to educate people that Mia was entitled to her opinions!

I am sensitive to the fact that many individuals with disabilities have a harder time "making family" from those around them. Some people, due to the nature of their disability, either significant medical fragility, or serious behavior challenges, have a harder time making and keeping connections. This is a message to those of us in the community who may know people in these situations – we can reach out to be that connection. I have learned over the years that in many ways our world is small world.

I am sure that in the audience here, many of you could say that another parent or family friend and not the formal system was the best source of information on "what to do next" for the person

you support, or gave you another vision of the future. I can point to a couple incidents in my life with Mia where another parent gave me a new look at what her life could be like.

What I am saying here, is that family is who you decide it is. Family is who you make it to be. We need to check our assumptions on who family should be, it needs thoughtful listening and reflecting, and occasionally adjustment. When I was working on my own end-of-life planning, I first appointed my sister and brother as Mia's trustees, figuring they are older, well-off, with financial experience and could manage without too much burden on their parts. I wanted my other two children, who I hoped would be having children of their own, to be free of this responsibility. My middle daughter reacted furiously. "They don't know the first thing about supporting Mia," she said. "You have to make me her trustee!" She was right. They don't. But Annie and her brother see Mia more often, know Mia's arrangements, what's important to her, and so I changed course to honor their wishes, of course, after checking with Mia.

Before launching in to reimagining support, I'd like to pause for questions or comments? You can enter them, if you haven't already, in the Q and A box.

In reimagining support, the same question applies. What does support mean to you?

When I started my tenure at the Georgia Council on Developmental Disabilities in 2001, the state had decided to include family support as a paid service in their 1915 (c) waiver. I was asked to write a white paper on what family support was, who would use it, what it might cost and the outcomes we might expect. I interviewed many people in the state who had been delivering family supports just as a way of supporting people, without a formal compensation mechanism. And I researched what was occurring in other states. I learned a few things early on which would inform my work in family support at the DD Council for the next 12 years.

First, the majority of families don't ask for much. In my research, the average requests for financial assistance ranged between \$2500 and \$5000, a one-time request, but many were far less.

And related to this, contrary to fears of state budget and policy staff, families rarely asked for more than what they needed and used money judiciously.

Second, families needed flexibility to spend the money on what they saw the need for. Creating categories of services or supports for families to check inevitably excluded the very thing that they knew would alleviate the challenge they were experiencing. Families knew what they needed better than anyone because they were living in the day to day.

Third, we had to make it easy to access. For one pot of money in Georgia's family support array, it was a two-page application. Making information widely available, through many doors, was key.

Fourth, if we allowed flexibility and easy access to this level of support, families, and the state could avoid the need for more intensive and expensive services, at least in the near term. At the time I worked on family support in Georgia, we estimated that for every two families we provided this low level of support, one person came off the waiting list for more expensive waiver services. What sense did it make to keep a family with a child on the autism spectrum who was a runner on a waiting list for a range of therapies and direct support when really all the family needed at the time was a \$2000 fence around the yard so their child could go out to play and be safe? Or funds to equip a sensory-quiet room? Or a swing? Or an iPad? So many inexpensive solutions kept families going.

Fifth, we learned that states with the most successful array of supports had what I referred to as a "three-legged stool." They had Medicaid waiver-funded services which by their nature were more restrictive, they had state funded services which could have been SSBG (Social Service Block Grant) or state funds resources and they had private foundation sources of funding.

There are a few lingering barriers to providing funded supports to family. First, in terms of Medicaid, dollars are directed at the person with disabilities and are eligibility-driven. They are not directed at the family as the recipient of services although families will tell you if they just

had a little support for themselves, they are much more able to support their family member with disabilities.

The second barrier with Medicaid is ironically universality – when we were trying to incorporate family support as a service in the Georgia 1915 (c) waiver, we learned we could not call it, or define it as “family support” because not everyone served by the waiver had a “family” available to them. So the service has the qualities of family support but is limited by an individual not having a natural family in their lives.

A third barrier in Medicaid funded supports is significant and goes back to the concept of helping someone in the shallow end of the pool so they don’t end up needing “deep-end-of-the-pool” resources. There are millions of people who don’t meet the eligibility requirements for federal entitlement programs. But they need some support to live on their own, be successfully employed, further their education or training, maintain relationships in the community and avoid encounters with the justice system. This was one of the more frustrating aspects of my experience in state government. Without access to some support, individuals in these circumstances and their families fell backwards into greater risk. The amount of time, energy, money and frustration some families expended just trying to access small levels of support or guidance, and the risks of their family members ending up in crisis vastly exceeded what the state could have provided at the onset of their need. It is probably not realistic to expect that the Medicaid program should provide these resources, so again, back to the concept of the three-legged stool, having several buckets of resources available to meet emerging needs.

In the last few years of my tenure at the Georgia DD Council, we began to think even beyond family support to community support. Instead of deciding how our grant money could be distributed based on our notions of what communities and families needed, we asked them to tell us what they needed and to propose how they would spend the money – the only requirement was that the funding was to support the entire community including people with disabilities, instead of supporting only the people with disabilities within the community. Turns out there is a very big distinction in this approach. It opened wide the awareness of the community to those in their midst who had been isolated. It expanded opportunities for people with disabilities and

their families – and it created families for some people who had been marginalized solely because they were alone. It was more sustainable because it began with examining and cataloguing the resources existing in the community and then building on them.

The emphasis on social determinants of health or social drivers of health contributes validity to this broadening of the definition of support. These are not new concepts, but are receiving renewed attention particularly in health plan work. More and more evidence reveals that physical health is only 20 to 30% of an individual's health status. The rest is determined by where they live, their housing or lack of, access to safe play or green space, employment status, domestic safety, access to healthy food and ways to prepare and store it. Affordable transportation. How much of “paid or formal support” supplies access to these things? How many of these elements are also related to social justice, racial and economic equity, equal opportunity? Wouldn't the best use of our funding be to ask families, “Exactly what is it you need to make your life easier, your ability to support someone else, easier?”

I'm going to backtrack a bit, summarize and then we'll open it for discussion.

First, families are who we decide they are.

Second, families know best what they need.

Third, asking families what they need instead of limiting resources to a set menu is more efficient and effective.

Fourth, resources need to be easy for families to find and access.

Fifth, support is most effective when it is timely, responsive and flexible.

Sixth, families are generally wise consumers of resources if they are offered in this way.

Seventh, families live in communities. So a good investment is developing communities to support families better. (SDOH approach)

Eighth, developing a few “buckets” of resources to meet the needs of families who may not meet rigid qualifications in any one bucket keeps people from falling into gaps.

I do want to mention another important aspect of family support to be aware of and that is to be cautious of families holding people back because of either their fear of individuals being on their

own, or their need for resources that are tied to the person with disabilities. When we were doing the work of developing family support, we had to make room for self-determination of young adults who wanted to leave their “families of origin” and make a life for themselves. Developing welcoming communities supports this. Supported decision-making supports this. Educating the community on the ability of individuals with disabilities to have lives independent of their families but still in relation with them, **JUST LIKE EVERYONE ELSE** is important to recognize and support.

In the end, the reason for reimagining “family” and “support” is to enable people to be part of community, like everyone else. Any time we plan places or programs for certain people that separates them from everyone else, the community loses something. Aren’t families smart enough to tell us what they really need? And aren’t we smart enough to develop supports and make resources available in the businesses and homes that already exist in the same community that everyone else lives in?

My experience says yes! What do y’all think?