

## TITLE OF PRESENTATION: “IS A FAMILY CONSORTIUM RIGHT FOR ME?”

As a young man or woman with disabilities begins to reach the end of their years in public school, they and their family often will turn their thoughts and planning toward the life they hope to lead as an active adult fully integrated into the community. By this time, they have been, hopefully actively preparing for this life by making and following solid transition plans in concert with their school and the adult service funders and providers they will be working with when school ends.

Many important questions have now arisen in this planning process that must be dealt with in a proactive rather than reactive fashion if they are going to achieve the fully integrated life in the community that they desire supported by the services they require and funded in such a manner that they can be assured these services and that quality of life will continue uninterrupted into the future after the parents are no longer there to lead the way and provide the means for that sought after life to continue.

Some of the questions on the minds of both the family of the individual and the individual themselves as they stand at the door ready to go out and enter that adult life might include such important ones as:

- I am at the age of majority, is guardianship needed to help with choices?
- Will I go on to some form of post secondary education?
- Will I seek employment after I graduate & can I go there directly from school or do I need some form of trade or vocational training?
- Where will I live and with whom?
- What supports will I require?
- How will I pay for what I need in the way of supports or cost to live items?

If the transition planning has been good and has included both traditional transition planning but also financial planning including the path to full employment while retaining full benefit eligibility then the individual with disabilities can feel prepared to walk through the door into adult life in the community. If on the other hand, this preparation work is incomplete or inadequate then more work can and should be done before the individual with disabilities fully enters their planned and hoped for integrated life in the community.

Marilyn and Joe Henn are the parents of a young lady with severe autism and significant behaviors, but no language who stood at that door with their daughter a number of years ago. They, and their daughter, had already traveled a long way on the road to this door. There had been times when they had fallen into the ditch on this road. There had been times when their daughter's inappropriate behavior had included kicking, screaming, biting, tantruming, smearing feces, publicly masturbating, jumping out of second story windows, pulling up the carpeting and eating the backing, banging her head through wallboard and six panel doors, pulling her hair out strand by strand until she was bald, self injurious behaviors (SIB's), eating foreign objects (pica), etc. Three times during their daughter's lifetime up until now while they lived in various states, they were told to institutionalize their daughter. Nancy, their daughter, requires constant 1:1 staffing, 24hours/day, seven days per week because her behavior is characterized by a low level of impulse control and must be managed and guided by external means using a version of behavior management called "Positive Behavior Support" which employs a proactive rather than reactive approach and seeks to understand the meaning of the behavior before deciding how to manage and guide the behavior in a more appropriate manner.

During this period where Nancy and her parents faced considerable obstacles to her future they formed a personal and professional "Circle of Supports" around Nancy and used a "braided" funding approach to fund her needs. At age 37, Nancy has achieved a great deal in her young life. She holds a full time job in at union scale with full benefits working for the Summit County Department of Office Services in downtown Akron, Ohio and has for nearly 15 years. Despite being in the bottom 10% by test of all those with autism, she is in the top 10% in the United States of those individuals in gross earnings and contribution to her own budget. During the last ten years she has won national recognition and two national awards in the United States. The first came in 1999 when she won the national award from the Association for Persons in Supported Employment (APSE) for "Personal Achievement". Then in 2003 she was the national United States award winner from the Autism Society of America for "Outstanding Individual with Autism". She was given these awards, not just for her work achievements which in, and of themselves, would be considered remarkable, but also for the high quality of her integrated life of recreation, leisure and residence in the community and the example she provides for others who seek to follow her.

One important and fulfilling aspect of her life is where she lives, with whom she lives and how the residential model in which she lives came to be. It is called a “Family Consortium” and it was not arrived at by chance or accident. When Nancy was moving towards her final years before graduating from high school, her family began to think about and actively explore residential options, realizing that Nancy could not live with them until she died and the responsible thing to do was to make provision for her residence for the future.

In the course of their investigation, they learned there was a continuum of residential options from least restrictive to most restrictive for individuals with disabilities and they must look at all of these options objectively and determine what was best for their daughter given her service and support needs which they knew very well. They discovered that the continuum of residential options stretched from independent living at the least restrictive end of the spectrum to institutions at the most restrictive end and that along the way were many different other choices and variations.

The Hennis never thought an institution was a viable choice. It was a model characterized by a “warehousing” type care model with too few staff and too many individuals with uncontrolled aberrant behaviors that would tend to cause their daughter’s life to deteriorate and offered little opportunity for ever being a functioning, fully integrated member of her community were she to enter that atmosphere. Their goal was to avoid this outcome for their daughter at all cost.

They had a similar view of nursing homes as a residential choice. Nursing homes were and are designed for people who need nursing care and were not an appropriate setting for their daughter who didn’t need nursing care and if she were to need it later, it could be provided as an Individual service plan requirement in a more natural community residence. Their daughter’s needs were more behavioral not medical in nature. They felt she could live in the community with supports and it was her civil and natural right to do so.

There were two other choices that they were aware of that they could have considered, those being foster care and skill development homes. They found that under the foster care model, an individual lives in a home with other residence just like they might do with their family and may even be the only individual with

disabilities living in that setting. The foster care setting may be a family or it might be a residence where caring people unrelated to the clients, are taking care of one or more individuals on a compensated basis. They learned that most foster care homes have oversight from whoever funds the care of the individual placed there and so they did a good job of watching out for the individuals health and safety issues, but were not really set up to handle behavioral issues or develop the full potential of the individual with disabilities by identifying and honing various daily and community living skills or assisting them in finding or maintaining employment and money management to name just a few needs. They also were meant to be permanent residential sites for the individuals placed there, but often were not because the foster care givers decided they no longer wanted to be in this business and exited it causing the residents to have to move to different settings. They were, in the main, best suited for individuals who needed little or no supervision except to see to their health and safety needs. Their daughter needed more than that. Skill development homes were an improvement on the foster care model because operators of these homes were trained to help clients with life and other skills, but still had many of the drawbacks of the foster care homes and so did not seem the right option either.

They looked at independent living as well, since this was the least restrictive option for Nancy, but were convinced that her need for supervision and oversight for health, safety, behavioral and daily living needs where she had deficits would not permit Nancy to live alone or even with someone dropping in now and then to check on her. This arrangement would work for some individuals with disabilities, but not for their daughter. They next considered having Nancy live by herself with either a live in direct care staff person or rotating direct care staff to take care of her service needs, manage her behavior and watch out over her safety and general welfare. Again, they decided this was not the way to go either. Nancy had no verbal capability and in a 1:1 situation without oversight by other people on a daily basis, she could be the victim of physical, sexual, verbal, financial or other forms of being abused and taken advantage of on a routine basis.

Their attention then shifted to the various forms of congregate supervised living that were available and they began to consider the pro's and con's of these choices. They knew that in the United States, and in the county in which they lived, the choices were funded by Federal residential Medicaid money, by local

county board of DD levy funds and by whatever the family themselves could contribute to the care of the individual about to be served. They learned pretty quickly that a full spectrum of services could be provided under these funding streams in a residential setting depending on what was called for in the Individual Service Plan (ISP) of the person about to be served and that included all of Nancy's service needs including daily living, behavior management, recreation & leisure, and health and safety. They learned Nancy could grow and develop the skills she would bring to this setting and develop new ones as well. They learned that supervised group living was not defined by a physical location. Forms of it could be found in apartments, duplexes, mobile homes, condominiums as well as traditional homes. They found it wasn't a function of how many people lived in the supervised setting since there were models in existence from 2, 3, 4 or more residents. It was more about the operating philosophy and who had a "say" in how important decisions were made that made one form different from another.

They soon learned the most likely forms of supervised group living that fit their daughter's needs for service and support were the "group home" and "family consortium" models. How then were they to decide what made each different and what was best for their daughter?

In a traditional group home, typically housing 2-4 individuals who are unrelated to each other, the residential, direct care provider who is picked to staff and operate the home usually by the principal funding source or the administrator of those funds on the funding source's behalf, hires and trains the staff and is the employer of record. The provider sets the home rules, receives the residents' funding streams and manages them, sets the activities, furnishes the home and both determines and handles all the home needs. The provider sets the philosophy of the home and the resident's ISP's are driven by the provider and the principal funders of service of the residents. Changes are approved exclusively by the direct care service provider, who makes all purchases for the home, watches out for the health and safety of the residents and reports on all this to the funding sources who are primarily, if not exclusively government entities at the federal, state or local levels. While this model overcomes some of the shortcomings of some of the other models the Hennis considered for their daughter, they felt that it was incomplete and not totally satisfactory either. The model tended to minimize family involvement and shut off family choice about what they wanted for their daughter. It also left the setting of the philosophy of

how the house would operate to the funder and the provider and that philosophy might be quite different than what the family wanted. It could include, for example, a largely segregated, sheltered workshop type life where the individual with disabilities' life was largely centered on going to a sheltered workshop and doing segregated recreational activities and events with just other individuals with disabilities and having no or little opportunity for a fully integrated life in the community with non-disabled peers and natural supports. This was not the life they sought for their daughter.

They then heard about and studied the "family consortium" model of supervised group living and became excited about this choice. It represented both full family involvement and choice, but "Best Practices" at least in the way care should be delivered for their daughter.

Family Consortia differ from group homes not in the physical settings in which they are found, but in the philosophy and choice by the family and the individual with disabilities in how they are operated.

In a "Family Consortium" model, which began in Ohio over 30 years ago, the residents and families choose each other and the provider and set the philosophy of the house. The Hennis Family Consortium philosophy is "Live, Work & Recreate in the Community". The provider and the families set the staffing pattern and with the residents determine the house rules. Home decorating is done by the families and all major spending decisions often including transportation systems are made by the families even if the funding comes from government agencies. The ISP development is driven by the families and the individuals served and all changes that affect all residents and the families are confirmed through the consortium itself.

Some responsibilities in this setting must be handled by the families and the residents served if they are truly going to be a "Family Consortium". These include picking the service provider, choosing each other (residents and families), setting the philosophy of operation and determining how the money will get spent.

Other responsibilities may be delegated or the families, in partnership, may choose to do these themselves as well. They include such things as owning and maintaining the home, hiring and training the staff (not having a direct care

service provider) letting staff make some purchasing decisions with oversight systems, paying the service provider to provide transportation in agency owned vehicles.

When families and residents choose each other they should:

- \* Share a common philosophy
- \* Want a similar life for their sons or daughters
- \* Have compatible disabilities
- \* Decide on same sex or coed to live together
- \* Have some financial means and access to funding sufficient for ISP'd services
- \* Be willing to reach consensus
- \* Be willing to abide by self-determined house rules
- \* Be able to adjust to having the individual live outside of their family home
- \* Be willing to reach consensus on decisions in partnership with the provider
- \* Be an active participant in the "Family Consortium" affairs

In forming a "Family Consortium" it is also wise to have a special needs attorney involved in forming the regulations and by-laws by which the consortium will operate. Issues like how people will come into and go out of the consortium including the cost to do so, what will be the expectations of family members, will the house be owned and kept up by the families, what will be the offices, how are you elected and what are your duties are just some considerations. You must also decide how decisions are reached (consensus is best), how benefits are protected for each resident by suitable wills and trusts, how members will be succeeded and how breakup will occur if it ever does.

The "Family Consortium" model isn't for everyone but for those who:

- Want choice in their individual with disabilities residential life
- Are willing to make a financial commitment
- Are willing to seek, find and choose compatible roommates, other families and a service provider who share their philosophy
- Are willing to see the other family members and their resident individuals with disabilities as extended family
- Have residents who are willing to "Leave the nest" and want to grow into the fully adult capable person they want to become

Then the “Family Consortium” model may just be the thing for you and your loved ones that encourages everyone involved to feel that walking through that door of adult life, at least residentially was a great thing to have done!

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