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*Equity, Opportunity, and Inclusion for People with Disabilities since 1975*

## **The HCBS Waiver Rule**

### **Changing the Way we Think and Act – Supporting People with Disabilities in the Community**

Change is hard – BUT, it presents an opportunity. The new regulations around the home and community-based settings rule will force states, through their providers and programs, to change settings and services that they have determined are not compliant with the rule. The challenge however, is not only in changing how and where services are delivered. A more significant challenge is how we change people's minds. The rule includes a new standard for transparency and communication with stakeholders, families and beneficiaries, and into that space has flooded a great deal of information that is confusing and fear-inspiring for caregivers and the people they support. For some people, stability in daily life was hard to establish, and the last thing they want is for the 'system' to take that away.

Caregivers and the people they support need a good foundation of information on which they can base their decision-making for a wider variety of choices that may result in people having more integrated lives in the community, without sacrificing their health, safety and security. There is overwhelming evidence from a variety of sources to support the premise that greater integration and involvement in the community, as opposed to engagement in segregated, disability-only services, enhances health, safety and security of people with disabilities. Supporting an integrated life in the regular community also supports individuals to "age in place" and to realize more of their hopes and dreams than if they remained confined in segregated settings.

States have up to five years, or March 2019, to do this work. No state can change things overnight. No one will lose services on March 17, 2015, like many providers have scared families into believing. But some services will have to get better – or end – in the next five years. What do we mean by "get better"?

#### **1. Health and Safety**

Is health and safety really the "gold standard" by which we measure supports for people with disabilities? Is this good enough?

The Council on Quality and Leadership conducted an analysis on the relationship between the factors in their Personal Outcome Measures survey and individuals' outcomes.

“Having looked at the data and listened to people’s stories, we studied which individual outcomes best predict the attainment of multiple outcomes? The regression analysis revealed these outcomes to have the greatest degree of predicting many more outcomes for the person:

- Exercising rights
- Choosing where to live
- Choosing where to work
- Performing different social roles

These outcomes, though not commonly achieved, are good predictors for the presence of several more important quality of life outcomes in a person’s life. Therefore, organizational efforts to provide supports that increase the presence of these four outcomes can have an even greater impact on the overall quality of life for people.” (A Word from Cathy Ficker Terrill; [www.thecouncil.org](http://www.thecouncil.org))

It would make sense that being able to exercise rights, choosing where to live and work, and having social roles that include friend, worker, family member, spouse, mentor, volunteer, member, athlete, etc., would result in an individual being able to accomplish more personal goals than if their experiences were limited. This makes sense for everyone, so why wouldn't this apply to people with disabilities?

## 2. Health and Relationships

Doctors and other health care professionals are beginning to appreciate the impact that personal relationships have on individuals' health, and particularly on their recovery following a significant health event. In a study of people with congestive heart disease, for example, the odds of survival for more than two years are up to **7 times higher** for people with frequent contacts, friendships, relationships, connections, and intimacy, as compared to **those without connections**. (Ornish, Dean. (1999). *Love & Survival : 8 Pathways to Intimacy and Health*. New York: Harper & Collin)

Yet, look at the relationship statistics of people in institutionalized services:

Relationship	Number	Percentage
Relative	495	39.2%
Paid	638	50.6%
Housemate	86	6.8%
Co-worker	41	3.2%
Unpaid Non-relative	2	0.2%
	1,262	100.0%

*(National Council on Disability (2012). Deinstitutionalization: Unfinished Business. Companion Paper to Unfinished Business Toolkit. NCD: Washington, DC.)*

What are the odds that the people in this sample have multiple relationships? Who is more likely to have the emotional support they need in the event of a serious illness – people in an institutionalized setting, or people who live in a real community?

### **3. Abuse and Neglect**

Many studies point to how social isolation and lack of bonding human contact resulted in permanent brain damage in children, difficulties in emotional regulation and physical changes to the brain. *(Spitz, 1945; Harlow, 1965; Nelson et al., 2007; Tottenham et al., 2010)*

Abuse is more likely to happen when three factors are present: power (of one person over another), vulnerability, and isolation. People with disabilities and seniors who receive services in settings that are typically only with other people with disabilities and paid staff are in this powerless status. *(Baladerian, N.J., Coleman, T.F., & Stream, J. (2013). Abuse of People with Disabilities - Victims and Their Families Speak Out. A report on the 2012 National Survey on Abuse of People with Disabilities. Spectrum Institute: Los Angeles, CA)*

### **4. Choice and Self-Determination**

Compared with institution residents, community residents have more opportunities to make choices, larger social networks and more friends. They access more mainstream facilities, participate more in community life, have more chances to acquire new skills and develop existing skills, and are more satisfied with their living arrangements. *(National Council on Disability (2012). Deinstitutionalization: Unfinished Business. Companion Paper to Unfinished Business Toolkit. NCD: Washington, DC.)*

### **5. One Agency's Mind-Changing Experience – Seeing IS Believing!**

In the fall of 2014, a provider agency from Tennessee (which provides services to people in congregate models of care) visited Katahdin Friends, Inc., (KFI) a community support provider in Maine which supports people using individualized and personalized supports in the community. These are reflections from the staff of the visiting agency who visited KFI to see what they do. These are excerpts, shared with permission from Gail Fanjoy, Executive Director of KFI.

Visitor #1: “Our trip to your agency was eye opening for us. You showed us what I had already realized, that our services are not really allowing people to fully participate in their communities because they are too geared to protection from harm and not enough with helping people connect in their communities and take the reasonable risks we all take in order to have a fulfilling life. We are

cocooning people in services in order to keep them safe, and this is leading to less independence, higher cost of services, more behavioral incidents and a negative reputation for people with disabilities.

My take-away from our trip is that agencies should help support a person's needs due to their disability, but not take on the responsibility for their life choices, or prevent them from making those choices. I also saw the huge benefit people get from their community connections. Many of the people we met and the staff that support them were assertively protective of the connections people made. And all of your staff spoke the same language and understood the dignity of choice and relationships with others who aren't paid to be there. As we begin re-visioning our own support services, this trip will be the catalyst for change for us. It will be interesting to see how this becomes reality in Tennessee."

Visitor #2: "During our time at KFI, I was particularly impressed with the staff and management. Not only were they friendly, professional and accommodating, but they all obviously believed in their service delivery system. Interestingly, most of the staff had no point of reference regarding facility based services. This was an unusual circumstance given how rooted facility-based services are in Tennessee. I was quite impressed with the level of confidence displayed by staff and people supported concerning community inclusion and integration. They were unable and seemingly unwilling to deliver or receive services any differently.

Another interesting topic was how Gail described the manner in which KFI challenged the state of Maine to allow them to "unbundle" services and only address the specific disability of each individual. This initiative likely made the single most significant change in how KFI was able to create individualized supports while remaining good stewards of the state's resources. Consequently, this brave approach allows reallocation of unused funding which made an even greater impact on people with disabilities.

Finally, the KFI experience brought forth a conceptual revelation concerning "Community Connectedness." Prior to the visit I was having some difficulty envisioning how people with cognitive/intellectual disabilities could coexist in mainstream society without an expensive support system. However, I bore witness to an innovative, cost effective and self-sustaining model of community connectedness that invigorated my belief and vision of Tennessean's with disabilities realizing these same liberties."

Visitor #3: "My recent experience visiting with Gail Fanjoy and the staff at KFI was uplifting and reminded me why I got into this field of working with people with disabilities. Their mission statement was clear from the beginning, that people with disabilities have the right to lead normal lives. It sounds simple, but with all the regulations, laws and policies we have to abide by, we tend to forget the basic things in life that people with disabilities have the right to enjoy.

KFI is a true example of an agency doing it right. They support people to become as independent as possible and to integrate into their community. They also support people's choices, goals and interests and allow them to explore their community, live in their own homes and find jobs that suit them. The

staff were non-intrusive in people's homes and showed respect, dignity and professionalism. I was very impressed with KFI's hiring practices, which include hiring people to work with individuals based on common interests, not just on experience in the human service field. This was evident when I met M. and his staff MN. MN was hired because he had a truck and had experience with engineering. He had never worked in the field of helping people with disabilities, but it was obvious that he was the best person to help M. with his small engine repair business. When I saw them working together in the garage, it was hard to tell who was staff and who was the person with a disability. Mike was obviously at his best, doing what he loved.

Another KFI practice that I found truly innovative was the flexibility in staff schedules to meet the needs of the people they support. KFI understands that people's lives change, their needs change, normal life doesn't always happen between 9am and 5pm, and that in order to truly support people becoming active in the community, they need to be flexible. The staff are trained to help promote community involvement and help people develop supports in the community, so that staff presence can be reduced. Although this type of scheduling can be beautifully chaotic, everyone at KFI understands this is the only way to really help people lead normal, independent lives.

Visitor #4: I really enjoyed getting to meet T., who came out of one of the institutions in Maine and I was so pleased and impressed by how far he had come. KFI supported him in buying his own home, maintaining a job for many years, visiting with friends and neighbors, as well as exploring his interests. Several times a week staff would take him down to the gravel pit where he could watch trucks and heavy equipment come and go. But it didn't stop there. Staff would help T. write down the names of the trucking companies and then do internet research with him to find out all about those companies. T. looked familiar to me as my agency serves many people like him, but the difference was that T. owned his own life and KFI was just there in the background supporting him when he needed it. If T. were living in Tennessee, I'm sad to say his life would look very different. He probably would not own his own home, he would have 24 hour a day support and his interests and hobbies would probably be classified as obsessive. This would lead to behavior modification and T. would probably be very unhappy. But by using KFI's approach of one person at a time, really getting to know the person, and helping them develop and live rich, meaningful lives, T. is thriving. We couldn't stay and visit as long as I would have liked with T. because he had to start making dinner for his friends who were coming over to watch a football game (how normal is that?).

KFI is really onto something and I'm so thrilled that I got to see it with my own eyes. Just hearing or reading about the KFI philosophy would not have the impact needed to resonate within me as I go about my work. I now have stories, examples and people to refer to when trying to implement some of this at my own agency and I'm so grateful to Gail and her staff for giving us this opportunity. Maine is very lucky to have a resource like KFI and I am so thankful for this opportunity!

Visitor #5: During a recent trip to Millinocket Maine, I had the esteemed pleasure of visiting KFI. When I was first informed about KFI and how the agency provided services and used the support of its entire community to help do so, my first words were how are they doing it, I just can't see it. Many of you have heard or used the saying "seeing is believing" or "a picture is worth a thousand words." Well, I am here to tell you, I saw and Yes I believe it and the pictures of people and all support staff truly

embodying KFI's mission and philosophy statement was worth more than a thousand words, it was priceless.

My heart was overjoyed to see how each person was so connected in their community. It was like being on the movie set of Cheers. At each site we visited in the community, everybody knew the name of the person entering that location. KFI 's support staff all recognize the importance of community involvement.

I was impressed as I visited the home of L. L. loved sports and he had several teams that he loved discussing with his staff. Both the staff and case manager takes the time to watch sports or do the research about sports so that they could always be engaged in the conversations with L. because that was important to him. L. also is a great speaker and has facilitated many forums. L. also presents during the hiring and orientation process at KFI. He makes it clear how he and other people supported want to be treated. It was evident that L. played an important role in his community. If L. wanted to go somewhere, he either rode his bike or was picked up by a neighbor or friend. If L. did not show up at an event or was not present at one of the local hang out spots, KFI would start receiving calls inquiring about the whereabouts of L.

My experience in Maine was a reminder on how important community connections are "because sometimes you want to go where everybody knows your name."