

Tying Funding to Individuals

Indiana has long valued the philosophy of individuals with disabilities having choice and this Task Force has further confirmed this with our values statement. We state in the Visions and Values “All Hoosiers with intellectual and other developmental disabilities have opportunities to use their gifts and talents to live a good life, with choice and control.” The other key statement in our Values is “Include a wide array of supports and services that are sustainable, equitable, and available across all communities.”

With those two value statements we as a Task Force have laid out a vision to maximize control of services for people with disabilities and place it in their hands. Therefore, funding attached to a facility bed must be eliminated.

Indiana has 2914 individuals in immediate care facilities for people with intellectual disabilities. An “Intermediate care facility/developmentally disabled”(ICF/ID is a facility that provides 24-hour support to developmentally disabled clients in a congregate setting. According to the Institute on Community Integration (UCEDD), University of Minnesota: National Residential Information Systems Project, Indiana ranks 42nd among States in where people are placed in an ICF/ID setting. It is clear states are leaving settings where people have less control over their living arrangements and services. This doesn’t mean all ICF/ID should close. ICF/ID’s do serve a niche and needed purpose of providing skilled care for people who have challenging medical needs and for individuals who require complex behavioral supports. ICF/IDs still pervasively go against this task forces goals in several key areas such as conflict free case management, size of settings in regard to number of residents in one setting, ownership of home / residence, and portability of service or choice for the individual. To better understand some of the points I will expand upon conflict free case management, ownership of home, and choice.

The lack of Conflict Free Case Management in ICF/ID settings offer no opportunity for the discussion of choice or the opportunity for the individual to progress along to a different or less restrictive environment of their choosing. The agency who receives the funding for the individuals is solely responsible for the day to day case management services. Therefore, this places the ICF/ID provider in direct conflict of interest of ensuring the funding is intact for their company versus acting without regard for the consequences of the company on behalf of the client. We as a State should recognize these conflicts and not allow them to permeate the services. I do want to state that their are ethical agencies which accomplish this in a credible manner, however, even the perception of conflict must be eliminated to ensure the full rights of an individual is respected and not even provided the opportunity to be violated.

The second key point to tying funding to the individual is to ensure the home or residence ownership is not held by the provider of service. When we link where the person lives to who provides the service we unwittingly restrict the choice of the individual receiving services. Sure, the individual could leave one provider and move to another but that might or in the case of ICF/ID’s would require them to move from their home to accomplish this. Imagine if in order to switch plumbers, lawn care services, or cable providers you had to move from your home. This would cause a conflict, where you

may end up staying in an undesirable situation or an unwanted situation longer than necessary or permanently just to be able to stay in your home.

Finally, ICF/IDs do not drive choice for people with intellectual disabilities. As stated previously, a controlled and closed environment provides limited choice to the individual receiving services. Some would argue ICF/ID facilities offer choice stating a person supported has the option to go on a waiver or enter an ICF/ID. States, however, do not limit access to ICF/IDD services nor have a waiting list. As Indiana progresses to community based services, where consumer choice is the cornerstone to all services we must do our best to avoid driving desperate families to ICF/ID settings rather than waiting 10 years for a slot on one of the state's waivers. Indiana's service delivery system should not incentivize families to institutionalize their loved ones.

The largest outlier of this is the need for the State of Indiana and all of us to be respectful of the businesses who have stepped up through the years by investing and providing care in the ICF/ID settings. The only way to do this would be to accomplish an organized transition to eliminate ICF/IDs. This can be done several ways. First the State would need to consolidate certified beds, and then eliminate open beds. The State would then need to setup a compensation platform for all closed beds which would take into account how long the asset has been in the program as an ICF/ID, how much has been invested and determine an adequate compensation to the provider for closing the bed(s). This same formula would be used to continue the transition away from this setting and towards the HCBS settings. Many would argue that if the setting is wrong or no longer appropriate or acceptable why are we paying providers to close those settings. There is a simple explanation to this question. Long ago the State of Indiana asked providers to invest in a program, which they did willingly in order to fill the service need and desire of the State and individuals. By doing this the State asked and committed to a partner. In order to keep that partner and ensure Providers will continue to rush into the gaps the State needs in the future it is imperative when a program is deemed to no longer be suitable and thus shuttered to compensate the groups who answered the call to action so that they will answer it again in the future, especially when they have invested in hard assets.

In conclusion, it is imperative for this task force to notice and identify areas where we lag behind or fail fellow Hoosiers compared to the rest of the United States, and being 42nd is not something we as Hoosiers desire. Therefore, it is important for Indiana and this task force to continue to advance services which move choice and control towards the individual receiving the service. This is a value we have always had and this is the value and vision the task force has adopted and this is why tying funding to the individual is the most logical way for us to proceed as a State.