

The “Waitlist”

What it Really Means for Citizens with Developmental Disabilities and Their Families

The Legislature funded the Waitlist: Why are we still talking about it? - RSA 171-A requires that funding be allocated within 90 days of need for citizens with developmental disabilities on the waitlist, although the legislature has not always appropriated sufficient funding to comply with the law.

The waitlist is a living document, constantly changing as more young adults graduate from school at 21 and need area agency services. The same is true for adults who have been receiving some support at home, but now need more services because they or their caregivers are aging. As a result, the need for additional funding will always be there and the waitlist will continue to be a priority.

What does it mean when a NH citizen who experiences a Developmental Disability (DD) or an Acquired Brain Disorder (ABD) is placed on the Waitlist for adult services at age 21 ?

- ***It means*** that person may experience the loss of skills amassed throughout their public school education experience affecting their opportunity to live as independently as possible.
- ***It means*** that person may lose their job and become unemployed because they will no longer have access to the job supports and staff needed to continue working and contributing.
- ***It means*** a parent or guardian may themselves need to leave their job to stay home and provide direct supports to their loved one, resulting in decreased income, hardships, as well as the individual’s loss of dignity and sense of independence.
- ***It means*** a family in this situation may no longer be able to pay their bills, keep their home or their savings, they may lose health care coverage. A once independent family may need and become eligible for state funded services.
- ***It means*** that the more people on the Waitlist translates into lost employment opportunities for the Direct Support Professionals (DSPs) who have dedicated their careers to the work.

What does it mean when children are placed on the Waitlist for In-Home Supports and Services ?

- ***It means*** the family may be headed into a financial and personal crisis, unable to balance the special needs of their child with the other needs of the family as a whole.
- ***It means*** that when the family can no longer cope without the necessary supports, their child may no longer be able to live at home with the family in their own community. It may become necessary to place the child in a residential or foster care setting at greater cost.
- ***It means*** that once a child is placed outside their family home, it is very unlikely they will ever be able to return home, and they may experience a lifetime of segregation and isolation.

Kelly's "Waitlist" Experience

In the early part of 1997, when Kelly was 15 years old, her mother Cathy was informed by Community Crossroads, then called Region 10 Community Support Services, that it was likely Kelly would *not* be able to receive services when she turned 21, due to a chronic trend of underfunding the Waitlist line item for Developmental Services. Cathy found that hard to believe, as she thought surely in six years, the legislature should be able to "figure it all out."

Fast forward to 2003. In May of that year, Cathy received a phone call many parents in NH dread; the Area Agency was calling to state that Kelly's status on the Waiting List was a certainty, and upon her turning 21 in June, there would be no services available for her due to lack of available funds. Cathy, a single parent of a single income household, worked full time as a small business owner as well as providing the wrap-around care for Kelly during the hours the school district was not providing them. Cathy faced the agonizing and unanswerable question;



Kelly Spinney, Summer of 2016

"How do I both provide all of Kelly's care 24/7 helping her live a good life, AND simultaneously go out into the world and earn the means to do all of that?"

The answer seemed reasonable at the time. Cathy decided to privately hire Kelly's support staff from her school years to continue supporting Kelly. To pay the wages, matching employer taxes, unemployment insurance (state and federal), workman's compensation insurance, and some modest benefits, Cathy decided to put all these expenses on her credit card. After all, how long could they keep Kelly on the Waitlist? Within 3 months, the credit card balance was reaching its maximum. The once temporary solution was fast becoming unsustainable.

The choice no family should ever wrestle with came soon enough. Cathy had to *either* break up her family and relinquish Kelly's guardianship to the state, *or* stop working, close her small business, lay off the several employees she had, and face the future as a homeless family with no income, and figure out how to care for Kelly and her younger school age brothers. Luckily, before this decision had to be made, Kelly received funding due to another person passing away. It should never come to this in our wealthy state. Families are willing to continue the work of supporting those they love, but doing it alone is not possible.

It's absolutely critical that with each budget cycle, our legislature fully fund Developmental Services line items, including the Waitlist for Services.