



END THE WAIT NEWS

Volume 1, Issue 1
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"How much of human life is lost in waiting?"
—Ralph Waldo Emerson

ABOUT NOEWAIT

In this, our inaugural quarterly issue of the NOEWAIT newsletter, we would like to inform you about who we are, how we got started, and what our plans are to end waiting lists throughout the USA.

NOEWAIT began in January 2008 after parents, several disability rights advocates, providers and others found one another via the Internet to discuss how to solve the problem of decade-long waiting lists and lack of appropriate services for people with intellectual and developmental disabilities in almost all states throughout the country. As many of the participants in these discussions had already been working on waiting list advocacy efforts in their own states, participants realized that a national effort that included as many stakeholders as possible had not ever been organized. Organizers recognized this lack of a national effort was impeding individual state efforts and was contributing to the lack of adequate funding and portability of services across states. The group started developing a national strategy. An independent high respected family and consumer run non-profit organization in Florida has joined NOWWAIT and agreed to serve as the fiduciary for our start-up period.

During the coming year of our start-up phase, the organizing committee has identified the following goals, objectives, and timelines we will achieve:



- Develop the organization's message & image
- Build a large grass-roots membership across the country
- Document the need & potential solutions
- Build organizational capacity & independence
- Reach public policy makers
- Raise public awareness & activate people

With each of these goals, we also have many action plans in place. Recently, we have been reaching out across the nation to invite people to become involved with the NOEWAIT listserv, which is our main gathering place. We have had interaction with other advocacy groups as well. Our website is on the Web and is updated regularly with stories about waitlists in many states. We have collected waitlist data from several states and continue to work on obtaining more.

Because NOEWAIT is a grassroots effort, we have started with no funding. We are raising money to keep us moving forward. Donations to NOEWAIT can be made through our Web site, at:

<http://www.noewait.net>

Join us in our efforts to end Waitlists for people with developmental disabilities. **We Can- We Will - We Must – End the Wait – Together!**

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WE PLEDGE

To unite the efforts of families, providers, government agencies, advocacy groups and citizens to change laws and policies across the country and eliminate waiting lists for people with intellectual and developmental disabilities.



THE HEART OF THE MATTER

Families waiting for services



I am Joy S., mother of three boys; Jake (9), and identical twins (4) Cade and Carson. Five years ago I was working as an RN with a BSN at Willis Knighton Hospital. I had been with the hospital for 7+ years making a great income. I was young and had a great family, and then my world turned upside down. A rare tumor was removed from my spinal cord February 11, 2002 and left me with left sided numbness and a neurological condition that has prevented me from working in the hospital again. As a result, I lost my job, benefits, identity and financial security. In the midst of all of this I was told I would never have any more children, but despite the medical prediction, I became pregnant with identical twin boys. Due to the neurological condition, my body was not able to carry the boys to term and they were born four months early, weighing 1 lb 14 oz and 2 lbs 2oz. They spent 3 months in the NICU and the three of us have accrued over \$750,000.00 of medical debt despite having insurance. We

make too much money to qualify for most state services, but not enough to pay our bills and pay for everyone's medications for the month. WE NEED THE WAIVER SERVICES. My boys have been on the NOW waiver waiting list since June of 2004. I was told that my son, Carson, who has the most moderate Cerebral Palsy and who requires assistance to sit, stand or walk, may be President of the United States by the time his name is called for the waiver services. This did not strike me as funny that day and it is still not funny to me today. This waiver service for my family can be the difference of Mommy getting her medicine that helps control her blood pressure, heart rate and keeps her functioning, and going without this so Carson and Cade can get their medicine this month. In our case, lives are dependent upon receiving these services. Thank you.

My name is Lynn. I am recently 24.

Today is my brother, Philip's 21st birthday. He is severely mentally handicapped.

I have two younger sisters as well. We used to have college funds. And then there were medical bills. And bills for summer camps So he wouldn't lose the few skills he learned during the school year. And money for special programs. That ended up not working Because my brother is still 'retarded.'

So now two of us are in debt The third is just starting college. Her story will be the same as ours. Yet, colleges don't care. And PHEAA doesn't help us. Our parents make 'too much.'

There is no budget yet, so he will not be able to work at XXX, which he had been doing one day a week while still in school, Until two weeks ago.

My mom, is on a ledge most days and usually I'm scared to death she's just going to end it all, my brother is difficult to deal with. I try to do what I can, to make it easier. But I have a daughter of my own, And I go to school full-time

I know one day, sooner than later, she will have another mental break down. And I know, she is not alone in this. So not alone.



She takes nearly as many pills as he does, just to function around him.

I love my brother, but yet I hate him too. And I know, deep down, whoever is reading this, you feel the same way I do.

I've defended him, to the point where I've been hit, beat up, punched, and nearly run over.

He was supposed to die by age 10.

He wasn't supposed to talk.

He never shuts up. That's the problem... he never stops talking.

But yes.

After I'm done law school, I'm going to get into ADA law, or something like the such, to help these kids. And their parents.

It's not their fault they're like this. But it's not their parents' fault either. And it wasn't my fault. Yes this is my life.

But, pass this on. To someone who might care. So that a budget might get passed. That will save my family, And all the other families, The suffering we endure.

DARKNESS VS. SUNSHINE

Florida vs. California: Two sunny states with two very different results

There was hope. Florida was eliminating its waitlist and was offering a rich array of supports for people with developmental disabilities. Now there is despair. Today, Florida has a waitlist of 18,000 people and has significantly cut essential services to the 30,000* people receiving waiver services..

As the waitlist increased even when new revenues were appropriated, the legislative reaction was one of frustration. Advocates explained that the new dollars simply met more of the needs of individuals already receiving services, but the legislature and a new Governor concluded it was an indication of greedy providers and families. Various efforts were undertaken to “improve” the management of the program and contain costs to free up dollars for people on the waitlist.

As a result, the rates paid to service providers were reduced. The caps established for service coordinators were increased and their rates were reduced. The Florida Legislature changed the laws governing the Home and Community Based Waiver in 2007 to establish a four-tiered system in which all but one “tier” had a financial cap or spending limit.

The Legislature further directed the state to use “a valid assessment instrument, client characteristics, and other appropriate assessment methods” to establish each person’s tier of service. Four waiver recipients and Southern Legal Counsel and the Advocacy Center for Persons with Disabilities filed a challenge to the proposed rules: *Moreland et. al. vs. APD, DOAH* case number 08-2199RP. They argue that the state has not designed a valid assessment instrument that assigns individuals to one of the four tiers thereby resulting in an arbitrary and capricious process. The plaintiffs have stated that all people receiving waiver services will be adversely affected by the proposed process and tier structure. Plaintiffs state: “Affected individuals will be left alone, will not be fed, will not have their hygiene and toileting needs met, will not be given the habilitation services or supported living services they require and will be denied services” They further argue that the state’s plan will subject individuals “to choosing between living under dangerous conditions and forced institutionalization.” They cite testimony from group home operators at a public hearing who stated that the plan “will subject group homes to close again forcing ... into institutions at great cost to the state.”

Clearly, the Florida Legislature is “robbing Peter to pay Paul” as a strategy to contain costs and free up dollars to serve people on the waitlist. Yet Florida’s expenditures for people receiving waiver services are about \$15,000 per person per year below the national average. The Sunshine State is not demonstrating reasonable support for people with developmental disabilities.

“The State of California accepts a responsibility for persons with developmental disabilities and an obligation to them which it must discharge. Affecting hundreds of thousands of children and adults directly, and having an important impact on the lives of their families, neighbors, and whole communities, developmental disabilities present social, medical, economic and legal problems of extreme importance.”

Section 1405 of the Lanterman Developmental Disabilities Services Act

The Lanterman Developmental Disabilities Services Act promotes the provision of services in the least restrictive environment and emphasizes community settings as the preferred living option for most consumers.

The Lanterman Act establishes an entitlement to services and supports for persons with developmental disabilities, those at risk of developing a developmental disability, and their families. This entitlement means that individuals with developmental disabilities and their families have the right to receive services and supports which will enable them to make decisions and choices about how, and with whom, they want to live their lives; achieve the highest self-sufficiency possible; and lead productive, independent and satisfying lives as part of the communities in which they live.

By making services an entitlement, California also must fund those services, which virtually eliminates waitlists.

Florida’s Tiered System

Tier# *Limited to individuals with service needs that:*

1. Cannot be met in tier two, three, or four for intensive medical or adaptive needs and that are essential for avoiding institutionalization, or who possess behavioral problems that are exceptional in intensity, duration, or frequency and present a substantial risk of harm to themselves or others.
2. Include a licensed residential facility and greater than 5 hours per day in residential habilitation services or individuals in supported living who receive greater than 6 hours a day of in-home support services. Total annual expenditures under tier two may not exceed \$55,000 per person each year.
3. Require residential placements, people in independent or supported living situations, and people who live in their family home. Total annual expenditures under tier three may not exceed \$35,000 per person each year.
4. Are in independent or supported living situations and those who live in their family home. Total annual expenditures under tier four may not exceed \$14,792 per person each year and a limited number of services and supports are authorized under this tier.



Legislative corner

MAKING CONTACT WITH LEGISLATORS

Whether on the state or federal level, legislators want most to hear from the people they serve and will respond very quickly when they receive many calls and e-mail messages from their constituents on a particular issue. They will also remember when they have never heard from a single constituent on an issue that comes before them.

Your representatives are people from all walks of life, just like you. You need not ever be intimidated by their position. They are there as your representative and are often very open to talking to you. On the state level, this interaction can be very personal.

These tips will help you to build relationships with your representatives that will help them to remember who you are when it is time to call them to support something you need. The public often does not get very involved in law-making. The problem with that is that many things can be changed that you are not aware of until it is too late. Getting to know your representatives is an extremely productive and important way to contribute to a better future for your child or for people with disabilities in general. It is well worth the effort, even when it seems initially intimidating or overwhelming.

HOW ELECTED OFFICIALS CAN HELP

Elected officials can make a significant difference in ending waitlists. We suggest that legislators:

1. Get out and visit services to individual with developmental disabilities. Find out what is really going on.
2. Have a panel of parents come speak with you and others, telling their side of the story.
3. Convene an interim committee to investigate and provide solutions to the waitlist problem.
4. Join groups and listservs such as your local Arc, NOE-WAIT, American Association of People with Disabilities.
5. Write and sponsor a bill increasing funding within your

Tips for Making Contact With Legislators

1. Go to Project Vote Smart (<http://www.votesmart.org/>) to learn who represents your district and how to contact them. Both state and federal listings are included.
2. Visit the Web sites of your representatives and sign up for their e-mail newsletters.
3. Watch for news from their newsletters or the newspaper that your legislator is having a community meeting, morning coffee meeting, or town hall meeting and make a point of going to the meeting.
4. Donate to their campaigns when they are running for election or re-election.
5. Volunteer for their campaign.
6. When there is an issue or piece of legislation that you **support**, make a personal call to them to thank them for it. Most legislators even publish their home phone numbers and do take calls at home.
7. Learn about your state's legislative session. When does it occur (varies from state to state)? What are they doing in the interim? (Sometimes there are interim committees that are important to you). All of this info can be found on your state Web site under "government".
8. Go to your state capitol during the legislative session or visit Washington DC. On the state level, sit in on committee meetings of interest to you. Legislators are accustomed to being stopped in the hall by lobbyists – but you can do the same thing. Stop them, talk to them about a bill they are sponsoring or an issue that concerns you.
9. Write a letter about the Waitlist in your state and tell them your personal story.
10. Talk to their staffers if they have them.

state to end the waitlist for individuals with developmental disabilities.

6. Write and sponsor a bill providing for portability in services within your state and from one state to another for individuals with developmental disabilities.
7. Meet and get to know the individuals in your state Developmental Disability Service organization.
8. Watch the dollars. Be sure they are not wasted on high salaries and other benefits that don't help individuals with developmental and intellectual disabilities. Become a watch dog.

WHAT WILL BECOME OF MY CHILD?

Medicaid Waivers: the Key to Services



"When my daughter grows up, I envision her living in a community-based setting – in a supported environment where she will have people who will make sure she gets her medications, has meaningful things to do, and where she is safe and living an adult life independent of me."

Sound familiar?

It is one thing to have this great vision. It is yet another thing to pay for it. The cost of this kind of care runs upwards of \$70,000 per year or more, depending upon the individual's needs and the state in which they live. The cost of care is more than many families earn in a year and is beyond their means to pay out-of-pocket. This is where Medicaid Waivers come into play.

Just saying the words "Medicaid Waivers" can make your eyes glaze over and instantly evoke the feeling of being overwhelmed for parents. However, knowing about waivers and how to get them is the most important thing a parent needs to know in order to realize your vision. It is also where waitlists exist, so it is very important to apply on time.

The Medicaid Waiver program is a federal and state program that provides funds for states to provide services to individuals as an alternative to institutional care. According to TASH, about \$3 of every \$4 that states spend for developmental disabilities services comes by way of Medicaid. In order to qualify for a Medicaid waiver, a person must first meet the qualifications of Medicaid itself. There are income requirements that have to be met.

Most states have some type of Medicaid Waiver program and usually have several. Typically, states may provide waivers directed to people with developmental disabilities and some states will also have programs for autism (although rare), other disabilities like traumatic brain injury and blindness, mental health, elderly, etc. To qualify for services under a developmental disability waiver, a person must meet the state's definition of developmental disability – and every state uses a different definition so it is important to know your state's definition so that you can prepare the proper documents and have the right testing to receive services. A person must also qualify for institutional care.

Each developmental disability waiver has a particular purpose: One may be to provide services and supports for a person while they live in their own home, and another provides a home and caretakers. The waivers have different names in different states. You can find information about your state waiver program, if it exists, by visiting the Web site for your state and either searching for "Medicaid waivers" or "developmental disability" or by finding the Health & Human Services Department of your state.

In some states like Colorado, if a parent wishes for their child to receive these services when they become adults, they may need to get their child on the waitlist while they are a teenager. Because of waitlists, this does not mean that the person in need will be automatically served by the time they turn 21. In fact, many will not. But when "slots" for services open up (meaning the state has enough funding to serve more people), they will determine who gets services largely upon the date the person became eligible.

No matter how dire the circumstance, in some states a family will not receive priority service if there are others before them on the waitlist who also have a crisis.

Every state also has a different system for accessing Medicaid waiver program. The Health & Human Services Department provides information about where to apply. Sometimes these services are managed through government "regional centers" and other times they are run through contracted local nonprofit agencies. Since states are obviously autonomous, the way programs are managed and what is offered will vary from state to state.

For more information about Medicaid Waivers, visit the following very informative Web sites:

TASH: <http://www.tash.org/mdnewdirections/medicaid.htm>

PAS: http://www.pascenter.org/state_based_stats/pick_a_state.php?url=http%3A%2F%2Fwww.pascenter.org%2Fstate_based_stats%2Fmedicaid_waiver.php&title=Medicaid%20Waiver%20Data

LISTING OF MEDICAID, MR/DD, DEEMING WAIVER, TEFRA & OTHER ASSISTANCE PROGRAMS: <http://www.geocities.com/HotSprings/Villa/1029/medicaid.html>

AUTISM WAIVERS:

<http://www.cga.ct.gov/2007/rpt/2007-R-0319.htm>

NEWS BRIEFS

NOEWAIT to Present at Reinventing Quality Conference in Baltimore

NOEWAIT has been invited to tell the NOEWAIT story at a prestigious national convention.

NOEWAIT is extremely pleased to have the honor of being invited to present at the National Reinventing Quality Conference in Baltimore, August 10-12.

www.reinventingquality.org/upcoming

Denver C. Fox, Ed.D., moderator and founder of NOEWAIT, will be presenting, and it appears that we will have other NOEWAIT participants who can also be there and assist in the presentation and communication with other agencies.

This is an unparalleled opportunity for NOEWAIT to get the word out about its national mission to end the waitlist and provide portability of services within and between states.

Colorado Waitlist Campaign Collecting Signatures for Ballot Measure

The Colorado Waitlist Campaign is collecting signatures to put a measure on the fall ballot for voters to decide. The measure is phased-in sales tax of 2 pennies on \$10 and will end the waitlists in Colorado. Information can be found at:

www.Endcoloradowaitlist.org

Prior to the ballot measure, the Colorado Legislature also allocated other funding for services for developmental disabilities and some counties also passed mill levies.

New Jersey Department of Human Services Sued Over Lack of Housing

The state of New Jersey's [Department of Human Services](#) is being sued by a legal advocacy group, [New Jersey Protection and Advocacy Inc.](#), for violating the rights of over 8000 developmental disabled people who have been waiting (over a decade, in some cases) to move into government-supported community housing.

<http://www.autismvox.com/sued-new-jerseys-department-of-human-services/>

Family Care Funding Cuts in Wisconsin

Wisconsin's new Long-term care plan for the elderly and disabled will not pay as much for services for family care.

<http://www.isthmus.com/isthmus/article.php?article=23024>

Florida Reduces Services, Rates

Florida is reducing the number of services and the rates paid to service providers in order to "reduce its deficit in the DD waiver." There is also fear that some providers will pull out of the state. Some services have been eliminated altogether while Florida continues to have a long waiting list.

<http://apd.myflorida.com/waiver/update.htm>

<http://apd.myflorida.com/providers/rate-reductions-notice.htm>

Sponsor a Radio Spot for NOEWAIT

If you own a small business - or know someone who does - or you work for anyone who might be willing to sponsor a spot about waitlists in the states of CO, WA, MO, TX, AK, GA, or OR, please contact Cathy Taylor at 1-866-808-6893 x217 to arrange to sponsor a spot. The cost for each spot is under \$200, which your company will pay directly to United Broadcasting. NOEWAIT has already supplied the message we want companies to pick up for us. So all you have to do is let Cathy Taylor know that you want to sponsor the National Waitlist spot. Your company name is in the spot and NOEWAIT has supplied a message.

How Many People Are Waiting?

Coleman Report - State of the States in Developmental Disabilities, 2008 reports

- 4,691,450 person with ID/DD in US
- 716,821 living with family caregivers who are 60+ years in age.
- 991,144 living with family caregivers who are 41-59 years of age

NATIONAL ORGANIZATION TO END THE WAITLISTS (NOEWAIT)

Po BOX 411
PARKER, CO 80134

E-mail: NOEWAIT@NOEWAIT.NET
Phone: 303-773-3890

The NOEWAIT organizing committee is made up of 16 parents, advocates, and representatives from agencies from eight different states. If you have questions about NOEWAIT, call Dr. Denver Fox at the number shown above.

We're on the Web!
www.noewait.net

10 WAYS TO HELP END WAITLISTS

1. Support efforts to make DD Services an "entitlement" in your state. When a service becomes an entitlement, the state must adequately fund it.
2. Join your state Stop the Wait campaign (www.stophewait.com).
3. Contact your legislators and ask them to sponsor bills to end the waitlist in your state and nationally.
4. Help NOEWAIT by recruiting members throughout the country to provide a national voice to our elected officials.
5. Talk to the media about the waitlist problem.
6. Investigate your state laws to see if your state has an initiative process whereby citizens can go directly to the voters to end the waitlist. Currently, Colorado is gaining signatures from citizens so that a ballot initiative to end the waitlist will be presented to the voters in November, 2008. Over half of the states in the country have some sort of initiative process. <http://www.endcoloradowaitlist.org>
7. Send a contribution to NOEWAIT through the website, <http://www.noewait.net>
8. Develop a movie using a videocamera to illustrate your own situation. Post it on YOUTUBE.COM.
9. Write a letter to your local newspaper telling your own personal story.
10. Download and use the NOEWAIT Power Point presentation and movie available at the website.

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