



# ANNUAL REPORT—2008

NOEWAIT—THE NATIONAL  
ORGANIZATION TO END THE  
WAIT LIST

## **NOEWAIT FIRST YEAR ACCOMPLISHMENTS**

The National Organization to End the Waitlist was founded Jan 19, 2008, by Denver Fox, a parent in Colorado concerned about the extensive wait lists for services and lack or portability of services from state-to-state for individuals with intellectual and developmental disabilities across the country, and the lack of a national effort to end those wait lists and gain portability.

For the first time in our Country our new coalition, NOEWAIT, was successful in starting a national Waiting List initiative for people with developmental and intellectual disabilities via email and within a short 3 months had over 200 members.

Using a spiraling technique of emailing to various groups and requesting the emails be resent to other lists, a beginning group of interested parents, professionals, advocates and self-advocates from all across the country was brought together using a listserv for communication and the sharing of ideas.

A smaller group, called NOEWAITORGANIZE was formed as the worker bees and the planners for the activities of NOEWAIT.

A Mission Statement was developed and agreed to:

**MISSION STATEMENT FOR NOEWAIT (THE NATIONAL ORGANIZATION TO END THE WAIT LIST THROUGH ADVOCACY, INFORMATION AND TRANSFORMATION)**

**BECAUSE**

Across the nation, people with intellectual and developmental disabilities wait years for services and supports and can not move freely from state to state or community to community.

**BECAUSE**

There must be adequate funding for lifetime services and supports needed by our most vulnerable family members, without gaps or delays.

**BECAUSE**

Funding must be available in all states, portable across and within states and promote self-determination for the individual with the disability, their families and legal guardians.

**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.

**We can, we will, we must end the wait - TOGETHER**

Over the course of the past year, through the use of 2171 Emails for the NOEWAIT listserv, and 3404 Emails for the NOEWAITORGANIZE group, one meeting of 5 members of NOEWAITORGANIZE and a number of telephone conferences and phone calls, the NOEWAIT group has accomplished the following:

**NATIONAL PRESENCE:** NOEWAIT has developed a national presence among individuals and organizations concerned with ending the wait lists for services and gaining portability.

**ADVISORY COMMITTEE:**

An Advisory Committee was developed including the following participants:

Val Bradley  
President, HSRI

David Braddock, Ph.D.  
University of Colorado  
School of Medicine

Steve Eidelman, Ph.D.  
University of Delaware

Charlie Lakin,  
University of Minnesota

Sue Swenson,  
Parent Advocate

## OUTREACH

Developed a NOEWAIT Power Point Presentation available on the NOEWAIT website (<http://www.noewait.net>) and presented to the **Reinventing Quality Education Conference in Baltimore**

Attended and presented about NOEWAIT at the **Community Access Conference** in Newark, NJ.

Developed a NOEWAIT Newsletter (<http://www.noewait.net>)



Developed NOEWAIT.NET Web Page (<http://www.noewait.net>)

Members did an extensive web search for contacts and emails, compiling a list of thousands of folks

Sent information to thousands of people through a Constant Contact list, conducting a nationwide campaign for members.

Inclusion of the NOEWAIT announcement and request for membership on numerous local, state and national newsletters, listservs, etc.

Wrote numerous letters and articles and blogs re NOEWAIT and wait lists, some published nationally.

NOEWAIT appears as a resource on Quality Mall

Passed out 100's of brochures and newsletters at conferences

## **INFORMATION COMPILATION**

Developed a Resource List for all States and a State-by-State Database

Developed a Database of Wait List Articles

Developed a Media and Important People Database

Developed an entry survey for participants in Survey Monkey

## **ORGANIZATION**

Developed NOEWAITORGANIZE as a working and leadership group.

Family Café assumed responsibility for handling NOEWAIT's finances. Began plans to further affiliate with Family Café

Developed a Communications Committee

Attempted to get reps in each state

Contact with Military Families on the Wait List

Letter to Geraldo Rivera

## EXTERNAL CONTACTS

Extensive Interaction with the National Arc regarding the Wait List Issue and inclusion of two NOEWAIT participants on the Arc Wait List Task Force

Conference Calls with a variety of national leaders

Meeting with Doug Rogers and Kareem Dale at the Democratic National Convention re: NOEWAIT, and additional Contacts with Rogers and Kareem Dale

Letter to Ted Kennedy and other political leaders

### About NOEWAIT

National Organization to End the Waitlists (NOEWAIT) is a grass-roots, national, social justice movement organized to ensure full opportunity, choices, freedom, and self-determination for people with intellectual and developmental disabilities in every community by eliminating extensive and long-lasting waitlists for services in every state. We exist:

#### BECAUSE

Across the nation, people with intellectual and developmental disabilities wait years for services and supports and can not move freely from state to state or community to community.

#### BECAUSE

There must be adequate funding for lifetime services and supports needed by our most vulnerable family members, without gaps or delays.

#### BECAUSE

Funding must be available in all states, portable across and within states and promote self-determination for the individual with the disability, their families and legal guardians.

#### 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.

NOEWAIT—dedicated to end the long waitlists for individuals with intellectual and developmental disabilities.

PO Box 411  
Parker, CO 80134

NOEWAIT



National  
Organization to  
End the Waitlist

I thought times had changed.



But I still can't  
live and work  
where I want.

**WE CAN,  
WE WILL,  
WE MUST  
END THE  
WAIT –  
TOGETHER!!**

[www.NOEWAIT.net](http://www.NOEWAIT.net)

## **POLITICAL**

Inclusion of one NOEWAIT participant on the Arc Policy and Planning Committee

Extensive participation of NOEWAIT participants in the Yes on 51 Campaign in Colorado to end Colorado's wait list.

Participation in the Consortium for Citizens with Disabilities

Participation in the Change.Org national campaign. Came in 2<sup>nd</sup> in the first round in Health Care. Change.org has announced their interest in working with to further our cause,

Sponsor of the Arc's Stop the Waitlist Campaign

Video developed for Geraldo's TV Show



## **PLANNING AND COMMUNICATION**

Development of First Year Goals and Objectives through the use of the Logic Model Process

Eight NOEWAITORGANIZE planning telephone conferences

## FUNDING

Three grants written and submitted

Fund Raising about \$1,000

## HOUSEKEEPING:

Established a NOEWAIT PO Box address:

NOEWAIT@NOEWAIT.NET

PO BOX 411, PARKER, CO 80134

Developed a NOEWAIT Brochure, available on the NOEWAIT website (<http://www.noewait.net>)

Developed a NOEWAIT Letterhead

Developed a NOEWAIT Logo



Waitlists are depriving people of their rights to life, liberty & the pursuit of happiness.

People with developmental disabilities are unable to obtain services to help them to work and cannot obtain housing because state and federal government have failed to fund the necessary services.

Waitlists for services for adults with developmental disabilities are a national disgrace. Some states have over 100,000 adults with extreme needs waiting for services. A few states have passed legislation to end the waitlists, but individuals in most states are fighting for services one person at a time.

NOEWAIT proposes national advocacy, awareness and coordination to solve this issue.

### Did You Know?

Over 4 million Americans have developmental disabilities. After they leave school, often at age 21, they move into the adult services category—for job services, day programs, home living situations, respite care, etc. Adult services are funded with “home and community based waivers,” which are markedly underfunded in most states. A young adult may wait years after high school to get services, and a person moving from one state to another must start over on the waitlist!



State waitlists can be longer than 30 years!

### Why is This a Problem?

- *Individuals are deprived of their rights - they cannot live and work where they want. Even if they do receive services, those services are not portable from one state to the next.*
- *Individuals lose valuable skills learned in years of training in the schools and in vocational transition programs.*
- *Years are wasted waiting without productive and appropriate programs in place for individuals.*
- *Aging parents are exhausted, lack resources to properly care for their adult children, often take themselves out of the work force to be caregivers, and must fight for services for their children. In many cases around the nation, parents have passed away, leaving their children with nowhere to go.*
- *Society loses the benefit of contributions from the individuals and their parents.*

### Please Join Us Today!

WE NEED YOUR HELP and talents to:

- Gather information about the extent of the waitlist in each state
- Get our message out across the country
- Contact elected officials to get them to take action
- Help us raise money for this valuable cause

NOEWAIT uses the Internet to gather interested people to work together on this cause. Our listserv connects parents, supportive friends, professionals, politicians, and advocacy groups. By uniting and mobilizing, we will gain the influence necessary to demand that Congress eliminate waitlists and allow for portability of services.

### What can you do?

#### Join the Listserv!

email us at [NOEWAIT@noewait.net](mailto:NOEWAIT@noewait.net)

#### Share Information!

#### Donate!

NOEWAIT is currently under the fiscal sponsorship of Family Café, a nonprofit organization. Donations should be sent to:

Family Café

FBO NOEWAIT

1332 North Duval Street, Tallahassee, FL 32303

Contact NOEWAIT:

PO Box 411, Parker, CO 80134

Email: [NOEWAIT@noewait.net](mailto:NOEWAIT@noewait.net)

Website: [www.NOEWAIT.net](http://www.NOEWAIT.net)

## PLANNING FOR THE YEAR AHEAD

- **SO MANY CHALLENGES. SO MANY CHANGES IN NATIONAL PRIORITIES AND CONCERNS!!**
- **CURRENTLY, A SMALL GROUP OF NOEWAIT PARTICIPANTS ARE WORKING TOGETHER TO PLAN FOR THE UPCOMING YEAR. AS THOSE PLANS COALESCE, THEY WILL BE PUBLISHED FOR OTHERS TO VIEW AND COMMENT, AND FOR REVISIONS.**

