

o n t a c t P O I N T S

JC Developmental Abilities Consortium

tion of Self-Advocates of NC, Inc.
Society of NC
njury Association of NC, Inc.
a Legal Assistance
for Recreation and Disability Studies
nical Center for the Study of
elopment & Learning
nity Living Association
mental Disabilities Services Section,
of MH/DD/SA
mental Disabilities Training Institute
Division of Women's and Children's
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Seal Society of NC
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Health Legislative Commission
Retardation Association of NC
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ships in Assistive Technology
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s S. Services Section, DMH/DD/SAS
Cerebral Palsy of NC
n Carolina Center Foundation, Inc.

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Services Needed

<i>Service</i>	<i>Child</i>	<i>Adult</i>	<i>Grand Total</i>
Unrecognized Code	23	1	24
Hourly Respite	229	107	336
Client Behavior Intervention	48	84	132
Case Consultation	29	20	49
Case Management	936	774	1710
Assertive Outreach	153	65	218
Screening Evaluation	263	84	347
Multi-Disciplinary Evaluation	141	23	164
High Risk Intervention	437	15	452
Outpatient Treatment	122	92	214
Physical Therapy	88	16	104
Speech Therapy	118	24	142
Occupational Therapy	114	43	157
New Periodic Code	255	218	473
Developmental Day Care	241	7	248
Unrecognized Code	16	0	16
Adult Day Vocational Program	56	1354	1410
Supported Employment - Individual	27	838	865
Supported Employment - Group	10	123	133
Sheltered Workshop	3	167	170
Day Activity	16	137	153
Partial Hospitalization	1	12	13
Psychosocial Rehabilitation	0	9	9
New Day/Night Services	40	52	92
Supervised Living - Low	11	418	429
Supervised Living - Moderate	5	246	251
Community Respite	177	94	271
Family Living - Low	8	52	60
Family Living - Moderate	53	107	160
Group Living - Low	17	310	327
Group Living - Moderate	61	931	992
Group Living - High	233	968	1201
State MR Center	2	32	34
New 24 Hour Service	59	112	171
Unrecognized Code	4	10	14
Transportation	69	111	180
Unrecognized Code	20	40	60
Service Left Blank/No Code	3	22	25
Grand Total	4088	7718	11806
Unduplicated Count	2138	5036	7174
Persons Counted Unknown			4
Total			7178

The Arc of NC • Dave Richard or Lee Covington • 16 Rowan St., Suite 204 • PO Box 20545 • Raleigh, NC
27619 • (919) 782-4632 • 1-800-662-8706 • FAX (919) 782-4634 • dave@arcnc.org or lee@arcnc.org

The Long Wait

Showing the significant of legislative decisions on the lives of 7,178 North Carolinians, their families and taxpayers.



Brandon is four years old and has severe cerebral palsy and epilepsy. He needs extensive physical, speech and occupational therapy. At the center he goes to, the all-day care services he needs are only available to those who have CAP.

Union County



After being on the waiting list since 1995, Doug's family has little hope of ever receiving CAP/MRDD services. **Doug**, age 22, needs these services to survive in everyday living and to maximize his potential.

Gaston County



Even though **Caleb** is ranked as a "high priority" for CAP/MRDD services, he has been on the waiting list for over one year. He needs communication devices because he is nonverbal as well as other items for improvement of life.

Durham County



Camille age 23, has cerebral palsy and has been waiting two years for an aide that will enable her to see employment opportunities. Without a CAP/MRDD-funded aide, she can't take advantage of the vocational training she has already received.

Wake County



Brad is a 23 year old with Prader-Willi Syndrome and functions in the severe and profound range of mental retardation. His family moved to NC from another state because of the better services offered. Now they are just waiting.

Gaston County

7,178

North Carolinians with developmental disabilities and their families are waiting for services. For them, waiting has become a way of life. Many of them have been on the waiting list for services for over 3 years.

The waiting list issue in North Carolina is a crisis.

The Waiting List: *A Matter of Conscience*

With **7,178** individuals with developmental disabilities and their families on the waiting list for services, **North Carolina has the 6th largest waiting list per capita in the United States.** And the number of people needing services is only going to continue to grow.

To even be considered for some services, and the inevitable waiting list, individuals and families must be in crisis. Individuals being considered for CAP/MRDD-funded services must be at risk of being placed in an institution.

Abbey Hudson is a five-year-old Wilmington girl who has Rett Syndrome and will have long-term and severe challenges related to daily living, communication and mobility due to her developmental disability. Research indicates that ongoing and aggressive therapies are necessary and can even prevent some of the chronic physical and medical complications related to this syndrome. Abbey has been on the waiting list for over a year and a half to get these necessary therapies.

To provide the services that she needs and that will allow her **to stay in her own home will cost about \$27,000 a year. To put her in a residential facility will cost \$75,000 a year.** Because up to the

waiting list tends to be longer for CAP/MRDD-funded services than for out-of-home placement, the only way the Hudsons may be able to get the services Abbey needs quickly is to put her in a group home.



But the waiting list is not strictly a financial issue. It's a matter of conscience. Why should people have to wait for years to get the help they need to lead more functional, productive lives? Rather than helping to provide ongoing, humane treatment and care for individuals with developmental disabilities and their families, North Carolina is forcing families to exhaust their own

resources, exhaust themselves and their support networks and often to make choices they don't want to and shouldn't have to before they can get the help their children need. Why should children be forced to leave their families in order to obtain services? Many parents of children with developmental disabilities are very capable and desirous of taking care of their child in their own home if they have access to the appropriate services.

As with the many types of disabilities, the types and costs of services for individuals with developmental disabilities and their families vary greatly. Many families only need respite care, therapies and case management. Others need more comprehensive services such as a group home.

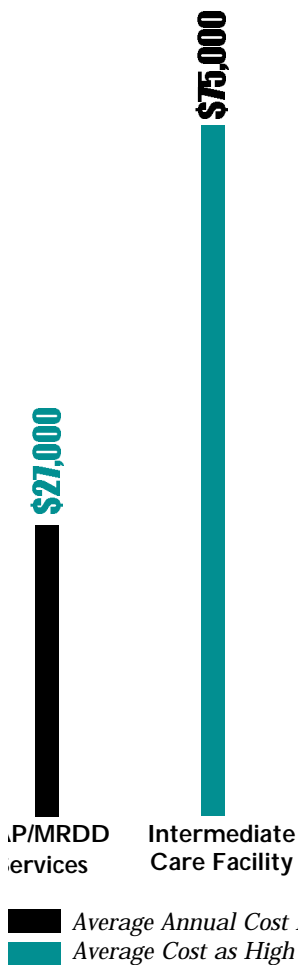
There is a solution. By approving the expansion budget for developmental disabilities, North Carolina's legislators can cut the waiting list in half in just a year's time. This means that children and adults with developmental disabilities, like Abbey, can get the services they need to allow them to maximize their potential and their families will no longer be in crisis.

Waiting List Sinks Family

I used to say we were doing okay whenever someone would ask how we were coping. The truth is, it's not okay anymore. I feel like someone has thrown me into the ocean with a 10-pound weight sewn into my lifejacket, and I'm sinking with that weight. There are programs to help people like me, families like mine, children like Timmy. Why can't we get the help these programs were designed to provide?"

The frustration that Ann Balogh, the mother of a son with autism and two other boys, feels is the common denominator among the people on the waiting list. Just how bad does it have to get before individuals with developmental disabilities and their families can receive the services they desperately need? How much do the individuals and their families have to suffer first? Why should they have to suffer at all?

As Ann put it, "Our marriages, our children and our sanity are at stake. How can we continue to function in our children's best interest when we are so stressed from day to day? I need the help that CAP/MRDD services would provide. I need to be able to be a mother to my children again, not the machine on auto-pilot I have become."



Taking Action Saves Money

The average cost of CAP/MRDD services is \$27,000 a year. These services include speech, physical and occupational therapy, supported employment, case management, community inclusion and respite. With these services, many individuals with developmental disabilities are able to remain in their own homes. Without CAP/MRDD services, some individuals with developmental disabilities have no choice but an out-of-home placement. The annual cost for an intermediate care facility is as high as \$75,000.

While CAP/MRDD funds cannot be used to pay for an out-of-home placement, many individuals with developmental disabilities who are in out-of-home placements do receive or are on the waiting list for CAP/MRDD-funded services.

interest P·O·I·N·T·S

What is a Developmental Disability?

A developmental disability is a severe, ongoing, mental and/or physical disability that was present before twenty-two years of age. A person who has a developmental disability may need life-long services planned and coordinated especially for him or her. People diagnosed with a developmental disability are limited in their ability to function in at least three of the following seven areas of major life activity:

- self-care
- receptive (understanding) and expressive language
- learning
- mobility (ability to move)
- self-direction (motivation)
- the capacity for independent living
- economic self-sufficiency

Examples of developmental disabilities include:

- mental retardation
- epilepsy
- deaf and/or blind
- cystic fibrosis
- spina bifida
- muscular dystrophy
- cerebral palsy
- autism
- traumatic brain injury
- sickle cell anemia
- spinal cord injury
- Down Syndrome



"I think it's a 'never list', not

The Boyd Family

Meet the Boyd Family

a 'waiting list. "

After spending over three years on the waiting list for services for individuals with developmental disabilities and their families, Susan Boyd holds out little hope for the help she needs to keep her daughter with autism at home and her family intact.

Kayleigh Boyd, age 7, has a developmental disability. Three and a half years ago she was diagnosed with autism. She also has scoliosis requiring a body brace that must be worn 23 hours a day, is mentally handicapped and nonverbal.

Because of her disabilities, Kayleigh requires round-the-clock care and supervision. She cannot feed, bathe or dress herself. She is not toilet trained. Her sleep patterns are erratic, often getting up at 3 a.m. for the day. She has no sense of right and wrong, safe and dangerous. She cannot communicate when or where she is hurt. There are dead-bolt locks on all the doors and appliances, and the only furniture in her bedroom is a mattress on the floor to keep her from hurting herself.

Her parents are exhausted and frustrated. "If it weren't for all the help we have received from Susan's family living in the area, I don't think we would have made it this long," according to Kayleigh's dad, Steve. "We are really struggling to keep our family together and our

marriage intact."

It's not that the services they need aren't available or there aren't enough providers. It's a funding issue. The average cost of services required to enable a person with a developmental disability to stay in his or her own home is \$27,000 a year compared to up to \$75,000 per year to place that same person in a group home. The cost of services that Kayleigh needs is in the \$12,000-\$15,000 range.

If the Boyds cannot receive the necessary services, the alternative facing them and many other parents is putting their child in a residential facility. Susan and Steve, along with Kayleigh and their five-year-old daughter, Jenna, toured a group home that had a slot for Kayleigh. There she would have received excellent care from doctors and numerous therapists. There were cooks, cleaners, counselors and a house mother. "There were about 10 people to do the job that I have to do," commented Susan. However, the Boyds declined the slot.

Like so many parents of children with developmental disabilities, their goal is to keep their child at home and keep the family intact. They



believe this can be done if they receive the services they have requested. While Kayleigh does receive some services through the public school system, her parents have requested services that will help them with personal care, self-help skills, play, necessary therapies and respite. "We should have a choice. I shouldn't have to make the choice of institutionalization so that my child can get the services that she needs," said Susan. "I'm not asking for a handout—just legitimate help."

In the meantime, the whole family suffers. There are no family outings. They cannot attend church or go on vacation. Steve and Susan can't steal a few moments for themselves to get the rest and rejuvenation they so desperately need, and their other daughter is also negatively impacted by their waiting list status. According to Steve, Kayleigh gets about 90% of their attention and Jenna gets 10%. "My other daughter deserves to have a mother who's not totally absorbed in the needs of one child," stated Susan.

interest P.O.I.N.T.S

Tom needs a more appropriate group living environment than the rest home he's currently in.

Johnston County

Kathryn has had to sell her home to fund the services her son with autism requires. She drives over 1,000 miles a week to take him to therapy.

Pender County

Derek is five years old and has autism. Because his family's insurance company does not recognize autism, they have no insurance to cover the speech and occupational therapy Derek needs. Currently, Derek does receive one hour of speech therapy each week through the public school system. However, his school does not offer occupational therapy nor does it provide sensory integration, which has been deemed critical for children with autism. In addition to therapy, Derek is waiting for respite care. He has been on the waiting list for two years.

New Hanover County

NORTH CAROLINIANS ON the 1998 Waiting List



<i>Area Program</i>	<i>Counties Served</i>	<i>Number on Waiting List</i>
Alamance/Caswell	Alamance, Caswell	121
Albemarle	Camden, Chowan, Currituck, Dare, Pasquotank, Perquimans	66
Blue Ridge	Madison, Buncombe, Yancey, Mitchell	337
Catawba	Catawba	148
Center Point Human Services	Davie, Forsyth, Stokes	311
Cleveland	Cleveland	202
Cross Roads	Surry, Yadkin, Iredell	166
Cumberland	Cumberland	184
Davidson	Davidson	176
Duplin/Sampson	Duplin, Sampson	65
Durham	Durham	113
Edgecombe/Nash	Edgecombe, Nash	97
Foothills	Alexander, Burke, Caldwell, McDowell	228
Gaston/Lincoln	Gaston, Lincoln	290
Guilford	Guilford	408
Halifax	Halifax	163
Johnston	Johnston	35
Lee/Harnett	Lee, Harnett	108
Lenoir	Lenoir	99
Mecklenburg	Mecklenburg	321
Neuse	Carteret, Craven, Jones, Pamlico	117
New River	Alleghany, Ashe, Avery, Watauga, Wilkes	111
Onslow	Onslow	379
Orange/Person/Chatham	Orange, Person, Chatham	274

<i>Area Program</i>	<i>Counties Served</i>	<i>Number on Waiting List</i>
Piedmont	Cabarrus, Stanley, Union, Rowan	241
Pitt	Pitt	94
Randolph	Randolph	50
Roanoke/Chowan	Bertie, Gates, Hertford, Northhampton	64
Rockingham	Rockingham	14
Rutherford/Polk	Rutherford, Polk	56
Sandhills	Anson, Hoke, Montgomery, Moore, Richmond	153
Smoky Mountain	Clay, Cherokee, Graham, Swain, Haywood, Jackson, Macon	237
Southeastern Area	Brunswick, New Hanover, Pender	299
Southeastern Region	Bladen, Columbus, Robeson, Scotland	222
Tidelands	Beaufort, Hyde, Martin, Tyrrell, Washington	77
Trend	Henderson, Transylvania	185
Vance/Granville/ Franklin/Warren	Vance, Granville, Franklin, Warren	103
Wake	Wake	691
Wayne	Wayne	76
Wilson/Greene	Wilson, Greene	137

interest P·O·I·N·T·S

Even after receiving state-funded vocational training, **Kelvin**, who has a developmental disability, is still sitting at home because he cannot get the supported employment services he needs to enable him to work.

Orange County

When **Jimmy** and his family moved to North Carolina from West Virginia, they had no idea that obtaining the services that Jimmy needs would be so difficult. Jimmy is 29 years old but because of severe, profound Down Syndrome he often functions at a 12-18 month level. In West Virginia, he was in a day program that taught him how to ride an escalator, ride public transportation and even bowl. He also held jobs stuffing envelopes, shredding papers and filling hospital baskets. During the 11/2 years that Jimmy has been on the waiting list for day program and respite services in NC, he has regressed significantly.

Brunswick County

Waiting List Facts

- 7,178 North Carolinians with developmental disabilities and their families are on the waiting list for services, more than will participate in the 1999 Special Olympic Summer World Games.
- The number of people on the waiting list has grown by more than 23% since January 1996 when there were 5830 people on the waiting list.
- North Carolina has the 6th largest waiting list per capita in the United States.
- The average annual cost of services funded by CAP/MRDD is \$27,000 per person. The annual cost of out-of-home placement is as high as \$75,000 a year.
- Services funded from CAP/MRDD sources do not have an income eligibility requirement but they do have a disability eligibility requirement. Many services funded by CAP/MRDD moneys help people with developmental disabilities be able to live in their own homes or more independently as adults in out-of-home placement.
- 4,292 people have been waiting 6 months for services.
- 3,408 people have been waiting 12 months for services.
- 2,012 people have been waiting at least 2 years for services.

(**Note:** there may be some duplication of people in these three time periods as they may be on the waiting list for different services for different lengths of time. The total number of individuals on the waiting list—with no duplication—is **7,178**.)