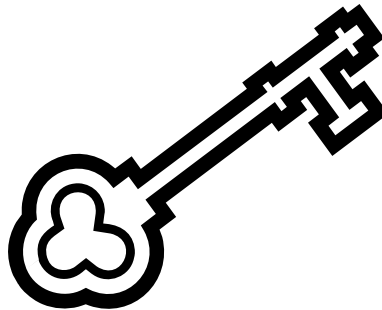


Maryland Department of Health and Mental Hygiene

# Developmental Disabilities Administration

The Waiting List Initiative  
FY 1999-2003

*A KEY OF OUR OWN*



**EXCEEDING GOALS – EXCEEDING EXPECTATIONS**

*Robert L. Ehrlich, Jr.*  
Governor  
*Nelson J. Sabatini*  
Secretary

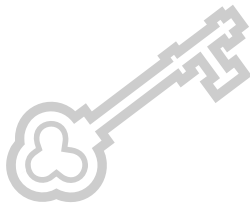
*Michael S. Steele*  
Lt. Governor  
*Diane K. Coughlin*  
Director

# **The Waiting List Initiative – Changing Lives**

## **Success!**

*Heather W. is happy!*

*As a result of the Waiting List Initiative, Heather moved into her own apartment in Salisbury, Maryland. Heather had been waiting for residential services for more than four years. During the early years of the Waiting List Initiative, DDA-funded support services were provided to Heather and her family in their home. After the sudden death of her father, Heather required more intensive assistance – she needed residential services. With funding available from the Waiting List Initiative, Heather was able to move to her own apartment with a roommate. She and her roommate enjoy shopping and going out to eat. Heather, who works close to home, has been enjoying decorating her new home. She is quick to tell the world how happy she is, and how much the Waiting List Initiative changed her world.*



## **History**

*The Waiting List Initiative is a tangible example of the power of individuals with disabilities and their families to make positive changes. Individuals with disabilities, families and advocates provided the impetus for the Waiting List Initiative through a comprehensive grassroots advocacy campaign. That campaign, which told the stories of thousands of Marylanders with disabilities, moved policy makers, legislators and the Governor to take significant and meaningful action to provide services to individuals on the waiting list for DDA services. In Fiscal Year 1999, individuals with disabilities and their families began to see the fruit of their work. More than \$34 million was provided in that first year to serve individuals waiting for services, individuals transitioning out of school and individuals in emergency situations. This ambitious project has translated into thousands of services since the beginning of the Initiative for individuals with developmental disabilities throughout Maryland.*

**The Waiting List Initiative  
Summary of Services Approved and Funds Committed<sup>1</sup>**

*Cumulative Totals (July 1, 1998 - June 30, 2003)*

	Services Approved	Funds Committed (annual)
Individual Support Services	2,024	\$11,087,123
Family Support Services	2,653	\$7,629,049
Residential Services	1,855	\$53,124,891
Day Services	2,374	\$30,770,958
<b>Total</b>	<b>8,906</b>	<b>\$102,612,021</b>

Since the beginning of the Waiting List Initiative, 8252 individuals who applied for services before 1/1/98 received at least one service by June 30, 2003. An additional 4208 individuals who applied for services between 1/1/98 and 1/1/99, received day or support services.

In addition to the progress made on services initiated and individuals served, DDA has increased Federal Financial Participation for services rendered to individuals with developmental disabilities by 162% since the beginning of the Waiting List Initiative. Many of the services provided under the Waiting List Initiative are covered under DDA's Home and Community Based Medicaid Waiver. For those services provided to waiver eligible individuals, the Federal government pays 50%.

**EXCEEDING GOALS – EXCEEDING EXPECTATIONS**

The Waiting List Initiative represents not only a funding Initiative in the State of Maryland, but also a systems change Initiative. This systems change resulted in more meaningful choices, greater control and improved quality of life for individuals and their families, a movement away from a crisis-driven system that responded only to dire circumstances, and expanded community capacity to meet the individual and unique needs of people with disabilities and their families.

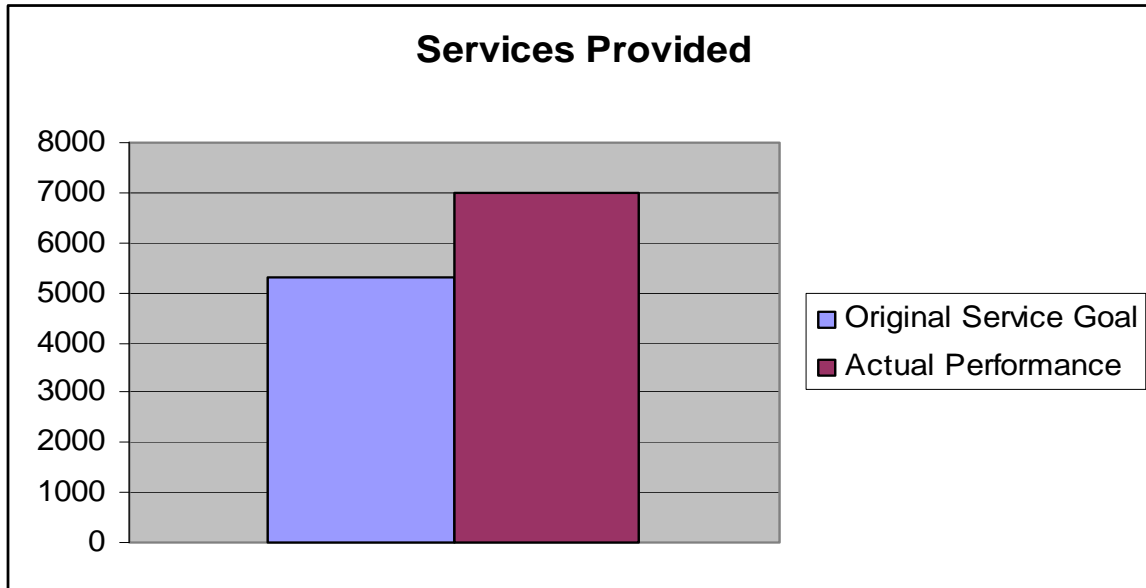
Through the guidance of the Waiting List Advisory Committee, DDA set forth priorities and parameters for the use of Waiting List Initiative funding. These guidelines provided the rules for expenditures including mechanisms to impact the nature of the services provided. As a result, funding was used in a manner consistent with nationally recognized best practices for residential, day and support services, was tied more closely to the individual than previous funding strategies and was instrumental in furthering the policies of the Administration aimed at improving self-determination.

In addition to the policy successes of the Waiting List Initiative, DDA provided more services to more people than originally targeted. As illustrated in the following graphs, DDA provided 6992 services with Initiative funding targeted specifically for individuals on the waiting list. This service achievement exceeded the original

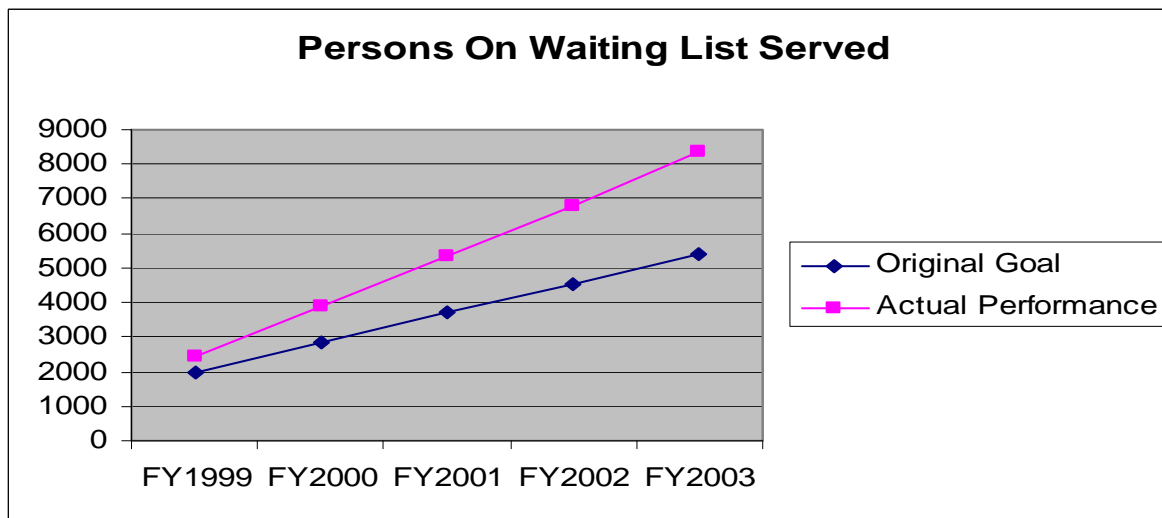
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<sup>1</sup> Summary excludes the following: Downsizing and Local Match (\$10m); Rate Enhancement (<\$16m); Cola/Inflation (<\$39m); Resource Coordination (<\$2m); and Infrastructure (\$1m).

goal by 1,677 services. In addition, the original funding for waiting list individuals was based on the waiting list figures available at that time, which indicated that 5,469 individuals were awaiting services as of 1/1/98. With those resources, and by supplementing that funding whenever possible, the Administration served 8,252 individuals who applied for services before 1/1/98. DDA exceeded goals and expectations by more than 50%.



DDA provided services to 8,252 individuals who applied for services before 1/1/98, exceeding the original goal of persons served by more than 50%.



## DAY SERVICES

### *What are Day Services?*

*Day Services are provided to individuals who are interested in gaining or improving daily living skills or skills necessary to enter the workforce. For many individuals, day services can include the support necessary for them to work successfully in the community (Supported Employment) or to own and operate their own business (Self Employment).*

During the Waiting List Initiative, 2,374 individuals received day services for an annual fund commitment of \$30,770,958. The Initiative marked a watershed in day services provided to individuals with developmental disabilities. More than 50% of day services initiated between FY1999 and FY2003 provide supported employment services for individuals. This is a testament to the capacity of DDA's community-based providers to evolve to meet the changing demands of individuals seeking supports. In addition to a growth in supported employment opportunities, DDA saw an increase in the number of individuals seeking to own their own businesses or otherwise design service and support models that directly responded to their unique goals and needs. The Waiting List Initiative enabled individuals to tailor their services to meet their specific needs. While traditional services remained available for those who wanted them, innovative options were also available, leading to improved lives and meaningful days for many individuals with disabilities in Maryland.

Overall, the average annual cost of day services provided through the Waiting List Initiative to individuals on the waiting list and transitioning out of school was \$11,464.

#### **MEANINGFUL DAYS**

*During the first year of the Waiting List Initiative, John was a 26 year old man living in his own apartment. He had a great deal of spare time, and began having trouble as a result of some social relationships in his neighborhood that threatened his ability to continue living on his own. With some assistance from his Resource Coordinator, John became acquainted with some positive role models and began an effort to launch a career that capitalized on his talent for memorizing sports and music trivia. With funding through the Waiting List Initiative, John received support to find a job as an assistant to a local radio personality. John found many new friends and discovered meaningful and rewarding ways to spend his time.*



## INDIVIDUAL SUPPORT SERVICES

*What are Individual Support Services?*

*Individual Support Services are services provided to adults living with their families or on their own. These services can be any type of support necessary for an individual to live successfully in his/her community. Examples of Individual Support Services include respite services, environmental modifications, adaptive equipment, money management and home skills.*

Over the course of the Waiting List Initiative, 2024 individuals received Individual Support Services. The popularity of these services demonstrates the determination of individuals with disabilities to live in their own homes in their own communities. It also illustrated for policy-makers the commitment of families to helping their loved one remain with them for as long as possible. Oftentimes, the same families who chose Individual Support Services under the Waiting List Initiative are the same families who had been providing unassisted care to their adult child for many years. Individual Support Services offer individuals the chance to have the supports they need in their own homes or their family home in the way that makes them the most comfortable.

The large numbers of individuals who chose Individual Support Services proved very helpful in the effort to serve as many people as possible through the Initiative. Over the entire Waiting List Initiative, the average annual cost for Individual Support Services was \$6,002. These generally low cost services often staved off a more costly out-of-home residential placement, allowing dollars to stretch to serve more individuals waiting for services.

### **SUPPORTS TAILORED TO THE PERSON**

*Charlotte has lived in her family home for more than 50 years. She has cultivated wonderful gardens which bring her much happiness. When her mother became unable to remain in the home and provide care for her, Charlotte had to leave temporarily. This absence was very difficult for Charlotte who wished to remain in her own home. Through funding for Support Services through the Waiting List Initiative, Charlotte was able to return home and have support staff come in to assist her. She also decided to share the joys of her home with a roommate.*



## FAMILY SUPPORT SERVICES

*What are Family Support Services?*

*Family Support Services are designed to help families stay together. Families with children with developmental disabilities typically experience emotional, physical and financial demands because the care and attention their children require tends to be intensive and indefinite. Family Support services are flexible and responsive to what the family needs, when they need it.*

Through the Waiting List Initiative 2,653 children and their families received Family Support Services. Many of these services, though low cost, provided essential supports to keep families together. These services, which could include respite for the family, any equipment to help the child stay at home or communicate more effectively, recreational activities and others, often make a significant difference for the family. This cost effective means of keeping families stable and together can often lead to long-term savings for the State, as families avoid crisis and, ultimately, out-of-home placements. During the course of the Waiting List Initiative, the average annual cost for Family Support Services was \$2,745 per person.

### **SERVICES THAT MAKE SENSE FOR THE FAMILY**

*Kim, who is a single mother of three girls, describes the Family Support Services provided through the Waiting List Initiative as a “godsend.” Kim’s middle child, Katherine, has multiple disabilities. The Family Support Services provide the family with needed medical supplies, adapted play equipment so that Katherine can play with her sisters, and respite so Kim can spend some quality time with the other girls, too. These services help address the specific needs of the family, which contributes to Katherine’s and her sisters’ success!*



## RESIDENTIAL SERVICES

### *What are Residential Services?*

*Residential Services are designed to provide a variety of support services to adults with disabilities in their living situation. People may be supported in a home that they own or lease or in a home owned by an agency that provides residential services. Some people live alone and others choose to live with other people to share expenses and/or companionship.*

During the Waiting List Initiative, residential services were offered to individuals who had aging caregivers. During the first year of the Initiative, DDA reached out to individuals who were living with caregivers who were aged 70 or older. In most instances, these were parents who had been providing 24-hour care to their adult son or daughter for decades. As the Initiative progressed and individuals received services, the option of residential services was offered to younger and younger caregivers until 2003 when the threshold was reduced to 55<sup>2</sup>.

Like other service areas of the Initiative, residential services provided valuable lessons for DDA and reflected the changing priorities of individuals with disabilities and their families. Most markedly during the first three years of the Initiative, the average cost for residential services through the Waiting List Initiative was far below the average costs for residential services overall. Because individuals and families were approached for services before a crisis occurred, services were able to be planned and thoughtful. This allowed individuals and families to choose providers who matched their needs and to receive services that were tailored for them. Additionally, many of the individuals to enter services during the first years of the Initiative had less complex needs and could be served with lower cost services. As the Initiative progressed and more individuals with challenging needs entered services, the average annual costs grew closer to the overall service costs that DDA experiences with all of its funding streams.

Many individuals, instead of moving into provider-owned housing, decided to get a home of their own in communities of their choosing. These individuals then accessed Community Supported Living Arrangements (CSLA). Not only did CSLA offer individuals the flexibility to receive intensive services in their own home, but it was also a more cost-effective service for the State. This can clearly be seen in Year 5 of the Initiative where the average annual cost of residential services in was \$47,171, while CSLA services had an average annual cost of \$24,324.

Throughout the five years of the Initiative, 1,855 individuals received residential services, including 580 individuals who chose CSLA. The overall cost of residential services through the Waiting List Initiative was \$31,437. This includes CSLA averages, as well, which, as mentioned above, typically cost less than traditional residential services.

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<sup>2</sup> Age of caregiver was as of 1.1.98

### **A HOME AND A JOB**

*During the first year of the Initiative, Don was 43 years old and lived with his 92 year old grandmother, who had many fears about what would happen when she was no longer able to care for Don. He had been on the waiting list for residential and job supports for many years. Don's grandmother was very relieved when funding from the Waiting List Initiative made it possible for Don to move into residential services and begin receiving supported employment from a provider close to her home. She was also pleased that his new living and working situations opened doors to meeting new people – she exclaimed “he’s not lonely anymore!”.*

Resource Coordinators played a pivotal role in the Waiting List Initiative. In addition to the services mentioned above, the Waiting List Initiative provided Resource Coordination to help individuals make choices about appropriate services and to help ensure that the services they receive are consistent with their individually developed plans. The comprehensive activities of Resource Coordination helped ensure smooth transitions for individuals receiving services and provided needed oversight to ensure that the services were appropriate.

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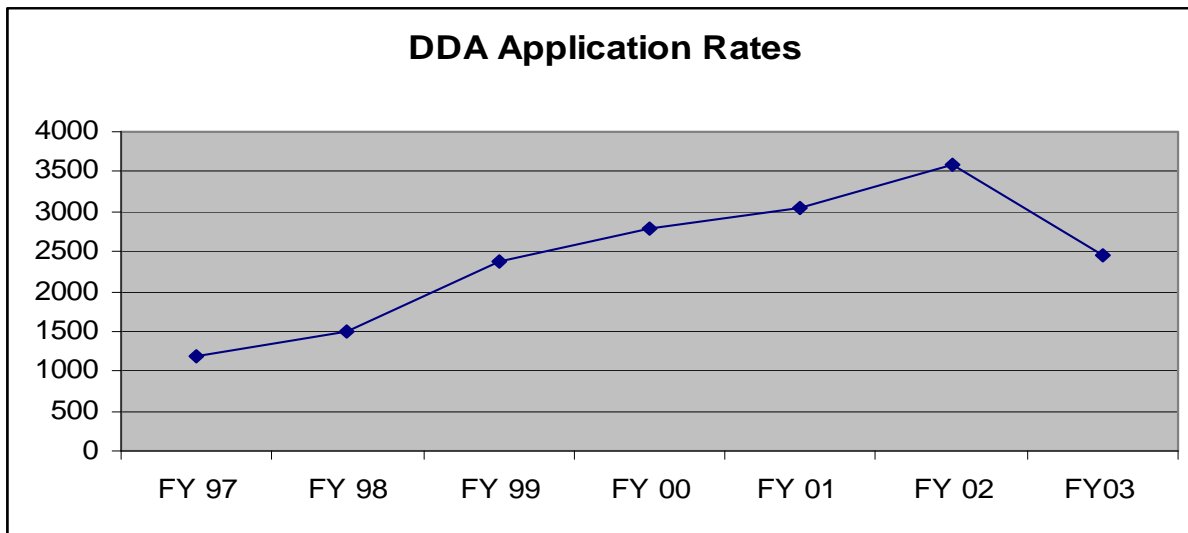
## **Application Rates – The Woodwork Effect**

After the inception of the Waiting List Initiative and the infusion of resources into the service delivery system, many individuals and their families applied for DDA services. This situation is referred to as the woodwork effect. Before the Waiting List Initiative, there was a perception that, unless you were dead or dying, your loved one with a disability would not receive services. As a result, Maryland had a great deal of latent demand for services. According to Gary Smith in his 1999 Report *Closing the Gap*, latent demand is defined as ‘individuals likely to qualify but who have not sought services and, hence, are not “known” to the system’.<sup>3</sup>

In Maryland, this latent demand turned into expressed demand in rapid fashion after the infusion of funding through the Waiting List Initiative. DDA’s application rates increased dramatically during the first four years of the Initiative. Based on FY03 numbers, it appears that this trend is leveling off and DDA anticipates that a steadier, albeit higher than pre-Initiative, rate of application will become the norm.

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<sup>3</sup> Smith, Gary; *Closing the Gap*; May 1999; Page 16.



A positive trend that DDA has identified within the increased application rates is that families of younger children are self-identifying earlier. This is a benefit to the service delivery system, as it provides a snapshot of future year system demands. It is also encouraging that individuals and families are identifying DDA as a resource earlier, thus allowing for greater planning opportunities.

## System Capacity

There is a demonstrated relationship between system capacity in states and the state's waiting list for services. System capacity is defined as the sum of (a) the number of individuals receiving residential services and [intensive] supports.<sup>4</sup> Basically, the assumption is that as a system grows to a certain level, it becomes better able to sustain itself through attrition in the system. Maryland has experienced monumental growth in its service capacity during the Waiting List Initiative. In the paper, *The Question of System Size*, Gary Smith examines the relationship of the system capacity and the waiting list. Mr. Smith indicates that "...when system capacity reaches more than 200 persons [receiving intensive supports outside of the family home] per 100,000 population, a state's waiting list is likely to be relatively small." As of 7/1/03, Maryland's system capacity stood at 124 persons in service per 100,000 of the general population.<sup>5</sup> This is a marked increase in system capacity from before 1998, where it is estimated that Maryland's system capacity was approximately 98 persons in service per 100,000.<sup>6</sup> However, it is still significantly below the threshold that will likely yield a reduction in waiting list figures. As the system capacity increases, the waiting list should correspondingly decrease.

Maryland has made unprecedented progress toward increasing the system capacity since the beginning of the Waiting List Initiative. The community services system has expanded in the following fashion through June 2003: 1855 new residential placements; 2374 new day or supported employment services; and 4677 new support services for children and adults living with their families or on their own. Despite this impressive

4 Robert Prouty and K. Charlie Lakin; *Residential Services for Persons with Developmental Disabilities: Status and Trends through 1997; Minnesota*

5 Figure based on number of individuals receiving residential (4620), CSLA (1353), institutional services (421), Individual Family Care (202), Purchase of Care (8) and 4% of ISS recipients (179).

6 The 2003 figure is lower than 2002 because of data clean-up activities resulting from implementation of new data management system

progress – a near 30% increase in those receiving residential or intensive supports since FY98, the need for additional community services continues.

The Developmental Disabilities Administration (DDA) has a broad two-pronged eligibility category for individuals receiving services. There are those who are deemed eligible as having a developmental disability (“DD-eligible”) and those who are determined to have a long-term disability that cannot be classified as a developmental disability (Support Services-only)<sup>7</sup>. Other states often take a narrower definition of eligible individuals. Some states serve only those individuals with mental retardation, while others stringently limit access to individuals with developmental disabilities who meet particular standards outlining their functioning limitations.

## **Summary**

While Maryland has made impressive progress by providing services to more than 8,000 individuals during the course of the Waiting List Initiative, there remain many unmet needs in the State. Individuals with developmental disabilities continue to need services and supports to enable them to live and participate in their communities.

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<sup>7</sup> COMAR 10.22.12