PEOPLE WITH DEVELOPMENTAL DISABILITIES IN NEW JERSEY
A PUBLIC POLICY WHITE PAPER

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(Note: Thirty years of study by the author while serving as Deputy Director of the Division of Advocacy for the Developmentally Disabled in the Department of the Public Advocate and Executive Director of the NJ Council on Developmental Disabilities led to this analysis. Data cited in it are from federally funded studies or from DDD itself.)

Introduction

This paper presents a comprehensive view of people with developmental disabilities in New Jersey and how they are served by DDD. It looks at how many they are, how many DDD serves and analyzes the inequities in how public funds are used to serve them now and how those could be used to serve more people more fairly and effectively in the future.

Historically, public policies affecting people with disabilities have been negotiated between the Director of DDD and parents groups and providers,. Once these parties have come to agreement, they have united to convince the Department of Human Services, the Governor's Office and the state legislature to adopt their policies and appropriate the funds to carry them out.

Those campaigns have played on the emotional appeal of the vulnerable people they represent, supported by those statistics and analyses that best make their case. Usually those statistics and analyses are incomplete and do not reflect the true numbers and real conditions and needs of all the people with developmental disabilities in the state.

As a result, public policies and spending have become distorted. Specifically, they have led to an unequal distribution of services: a few get more resources than they need and many get little or nothing. This is not only inequitable but also wasteful, leading advocates and DDD to request more resources before they use the ones they already have effectively and efficiently

People with Developmental Disabilities in New Jersey

By definition, people with developmental disabilities have severe disabilities that they acquire before age 22. Most have mental retardation, cerebral palsy, spina bifida, epilepsy or autism or a combination of those diagnoses.

They make up a small percentage of New Jersey's population-less than 2% of the total. They also make up less than 10% of the state's citizens with disabilities. They receive more than 6% of the state's total budget, more than all people with other disabilities.

Most of it (over $1.1 billion) comes from DDD. The Department of Education's Office of Special Education and local school districts spend almost as much but some of those funds support children with disabilities other than developmental disabilities. Other state agencies contribute small but significant sums that have never been added up.

There are about 1.7 million people with disabilities in New Jersey. Only 150,000 of them have developmental disabilities. DDD serves 34,000 of them. Most of the rest get no state services. Most live with their families, although about 25% live on their own or with a spouse.

Policy Analysis: There will never be enough money to serve all the people with developmental disabilities in New Jersey as they are being served now. Currently, there are great inequities in who gets what. Because there is no legal entitlement to DDD services, these inequities will continue unless DDD revises its policies and practices to assure that its resources are distributed equitably and used effectively. That will only happen if the Administration and the state legislature insist that DDD do so and condition any additional funding on the demonstration that it has taken effective action to do so.

How DDD Uses Its Resources

DDD spends about $160,000 annually on each person in its seven developmental centers. There are about 3,100 of them and they take up more than a third of DDD's budget.

4,005 live in group homes and get day programming at an average total cost of about $83,000 a year per person. 1,060 live in supported apartments at an average cost of $55,400, including day programming. 504 are in supported living at a cost of about $22,000 a year, including day programming. 1,568 live in foster care at an annual cost of $33,467 each including day programming. A small number are in nursing homes or out of state placements.

(Note: the average cost of day programming [sheltered workshops and other supervised daily activities] is $14,000. On average, people in supported apartments and supported living are less likely to be in day programs and are more likely to be gainfully employed and thus contribute to their own support than are those in group homes and foster care. This is primarily the result of their greater community integration through those programs.

6,500 get family support that averages $6,000 a year, much of it for respite care. A few also get day programming and transportation services in addition.

The majority of DDD's clients only get case management services that may amount to no more than one phone call a year.

Service Inequities

If all DDD does over the next ten years is eliminate the inequities described below, it could double the number of people it serves from 34,000 to 68,000 with comparatively little additional money in 2005 dollars.

That is because the amount and kind of services people now get from DDD bear little or no relationship to what they need.

- Developmental Centers

Until the end of the 1970s, institutionalization was the only significant service provided by DDD. There are still people living in developmental centers who were placed in them when DDD had few if any other options to offer.

Professionals who have examined the matter agree that at least 1,500 of the 3,100 people now in developmental centers could live in the community at much less cost and would like to do so. Those considerable savings depend on closing centers so that all of their administrative and service budgets can be used to create community living arrangements for their residents.

For example, the closing of North Princeton Developmental Center in 1999 paid for all its former residents' current placements. It also provided an extra $10 million annually to increase community medical and mental health services available to anyone with a developmental disability in the community. That was possible only because the entire facility was closed.

(Note: *The Plan to End the Waiting List by 2008*, mandated by the state legislature in 1998, called for the closing of three developmental centers by that date at savings estimated at $30 million annually. For several years, legislature appropriated the funding recommended in the report. However, the Administration never followed through on its own recommendation to close those centers and capture the resulting savings.)

Parents of a few developmental center residents have vocally opposed closing any other centers. While there are at most 200 of them, they have the political and financial support of the state and national unions whose members work in those centers as well as considerable, if misguided, sympathy from the media. Thus far, they have succeeded in blocking further center closings, even refusing to consider dropping their opposition to such closings in exchange for guarantees that their own children can continue to live in the centers that remain open.

The major arguments for retaining developmental centers are that they provide a safe environment for people who are most vulnerable because of the severity of their disabilities and that they also provide services for those with severe disabilities that can't be provided elsewhere. Both arguments have been disproved.

Recent investigations of two of the seven developmental centers run by DDD by the U.S. Department of Justice (DOJ) found that they failed to protect the health and safety of the residents. They found hundreds of cases of broken bones and wounds requiring sutures that were self-inflicted or caused by other residents or staff. They also found hundreds of cases of improper or unsupervised use of psychotropic medications, often administered for a year or more without medical review.

In both cases, these investigations were triggered by widely publized deaths at each center but resulted in disturbing findings that were not related to those deaths. There is no reason to believe that similar investigations of the other five centers would not produce similar disturbing findings. DOJ is looking for legal justification to investigate additional centers.

The failure to protect the health, safety and civil rights of people in developmental centers is not unique to New Jersey. Across the nation, virtually every investigation has exposed similar failures. Prevailing professional opinion holds that, over time, it is not possible to operate such facilities that do not produce abuse and neglect. There is a substantial body of research-based literature explaining why that is and none that supports the opposite conclusion

A number of studies have found that there is no correlation between the severity of physical or cognitive disabilities and success in moving from developmental centers to community living, although there is a negative correlation between success and behavioral problems. Ten states and the District of Columbia have closed all of their developmental centers. Several of them have created community residential programs for those whose behavioral problems make the transition from institutions to the community difficult.

Like most other states, New Jersey has downsized its developmental center population. However, it lags significantly behind most of them.

It ranks third, behind California and Texas, both states with much larger populations, in the absolute number of people in developmental centers. It also ranks third behind Arkansas and Mississippi in the number of people per capita in centers. Neither of those states have the extensive system of community residential programs in which to place center residents as New Jersey does.

Since North Princeton closed in1999, the developmental center census has dropped from 3,500 to 3,100. The Department Human Services (DHS) has attributed this decline to its efforts to place people from centers into the community without closing any of them. An analysis of the numbers belies that claim.

In 1999, the annual death rate at all centers was about 100 and rising steadily because of the aging of the population of the centers. Thus, attrition through death more than accounts for the decline in the centers' census in the last half dozen years. That means

that DDD has actually admitted more new residents to developmental centers during that period than it has placed from them into the community.

Two factors explain that phenomenon. First, New Jersey, unlike many other states, is still using its developmental centers for emergency placements, instead of building that capacity and the responsibility for providing it into its community programs. In fact, DDD routinely accepts people with behavioral problems into centers at the request of their community providers, even though those providers' DDD contracts contain funds to hire their own behavioral specialists to deal with such problems.

Second, DDD has been slow to place center residents in the community despite legislatively appropriated initiatives in SF/Y 2001 and SF/Y 2002 budgets to place 344 of them as a good faith effort to meet its obligations under the U.S. Supreme Court's Olmstead decision. While DDD has recently stepped up efforts to make such placements, 151 0f those 344 residents are still waiting to move to the community after three years even though money has been available to move them for that long. The DOJ investigations found this is a violation of their civil rights.

Policy Analysis: The continued placement of 1,500 or more people in developmental centers who could live in the community is a violation of the Olmstead decision that entitles them to treatment in the least restrictive environment appropriate to their needs. It is also an enormously wasteful drain of DDD's resources. Even if DDD placed all 1,500 in group homes, its next most expensive option, it could place an additional 1,500 of now unserved people in that same expensive option.

To achieve these badly needed savings will require the Administration, with the support of the state legislature, to insist that DDD close three developmental centers over the next ten years. (It takes about three years to close one.) It will also require both of them to resist the pressure of the tiny minority of parents and their union supporters who oppose such closings. To do so, both will have to educate the media and the public about the pressing need to do so and to the benefits that will produce for the residents and the additional people it will enable DDD to serve.

It will also require DDD to close further admissions to its developmental centers. That can only be done by creating the capacity community-based emergency placements and by insisting that providers use them or use contracted and/or community resources to deal with behavioral emergencies.

- Group Homes

Group homes were first developed in the 1970s as an alternative to developmental centers when the movement to close those centers began. They were attractive to parents because they appeared to offer many of the safety features they had sought in the centers.

In 1978, DDD had to move 2,000 developmental center residents into the community to meet federal living space standards to qualify for newly available matching funds to run

those centers. At the time, there were only six group homes in the state, all run by county Arcs with non-DDD funds. DDD needed to expand the number of group homes enormously and quickly.

It made the critical decision to offer the existing parent advocacy groups, such as county Arcs and UCPAs, the opportunity to contract to run group homes. DDD made this offer more attractive by including a 10% administrative add-on to its service contracts. Because group homes then cost between $150,000 and $200,000, this gave the agencies an opportunity to expand their executive salaries, staff and administrative facilities considerably.

Over the years, this has radically changed the nature of those organizations, shifting their focus from advocacy to service provision and shifting much of the power within those organizations from parents to the ballooning administrative staffs needed to run those rapidly expanding businesses. Modest offices were replaced by palatial, free-standing buildings and executive salaries increased accordingly. These changes were further accelerated when DDD contracted with these agencies for almost all additional community services.

Thirty years of experience have revealed that group homes are not effective community placements for many of the people who live in them. They do not lead to real community integration because the residents of the group home do things as a group and have little opportunity to interact individually with their neighbors. Activities are organized around the use of the group home van and the convenience of staff. If Thursday is bowling night, everyone goes bowling whether they enjoy it or not.

The structure of group homes unnecessarily limits residents' choices in other ways as well. They eat what the group eats, like it or not. More importantly, they have no say about who the other four or five people are whom they will spend the rest of their lives with and often don't even choose whom they share their bedroom with.

While some people have disabilities that benefit from the structure and supervision group homes provide, many do not. People who have moved from group homes to more independent forms of community living overwhelmingly prefer the latter. Many group home residents the Council has interviewed for its publications vociferously express their desire to live more independently. These observations are borne out by an informal survey conducted by DDD, which determined that fully 80% of current group resident are capable of living in less restrictive and less costly placements.

Until two decades ago, predominant professional opinion called for a continuum of services so people could progress from one level of independence to the next as they learned the skills to do so. Experience has discredited this notion of 'readiness'. Many residents of North Princeton and developmental centers in other states have successfully moved from those centers directly into their own apartments, instead of group homes.

Across the country, there has been a growing recognition that states have over-invested in group homes. Some have quit acquiring them and others have begun to close some of the ones they fund. New Hampshire has closed them all in favor of more individualized living arrangements.

New and Expanded Options for Individuals with Developmental Disabilities and their Families, DHS's 2002 blueprint to reform DDD, acknowledged that New Jersey had too many group homes and needed to devote its resources to creating more individualized living arrangements. Despite that acknowledgement, DDD's last two budgets have included funds to create 134 additional group homes and there is talk of a bond issue to build still more.

DDD now funds approximately 700 group homes, more than one for every municipality in the state. Altogether, the state's various agencies fund about 1,500 community congregate living facilities, most of them in poor or middleclass communities. Most are non-profit and cut into the local tax base. Because they house groups of people who are not accepted by they neighbors, they attract more community resistance than do people with the same characteristics who move into the same neighborhoods individually.

The continuing increase in group homes is a function of the lobbying of statewide provider organizations, many of whose members benefit more financially from them than from other forms of community living. At least some of that lobbying is paid for directly or indirectly by administrative funds from DD contracts.

It is also a result of the failure of DDD and advocates to effectively educate families and policy-makers that many people with disabilities now at home, in group homes and developmental centers can live more happily and successfully in individualized placements that cost much less than group homes do.

Policy Analysis: DDD is wasting funds that could serve others with unmet needs by providing group homes to many who could live better in less costly placements. It has admitted that it must reduce its over-reliance on group homes. This will require it to develop procedures to identify current group home residents who can live more independently, to create incentives for providers to move them into such placements and for it and the state's policy-makers to resist the political pressure from some providers to add unnecessarily to New Jersey's surplus stock of group homes.

- Racial Inequities

There is a strong correlation between the incidence of developmental disabilities and poverty. That is the result of the lifestyles of many poor mothers-inadequate nutrition, teen-age pregnancies, substance abuse and lack of pre-natal care. Since African-Americans make up a disproportionate share of New Jersey's poor, more of them have developmental disabilities than other ethnic groups. Per capita, there are one and a half times as many African-Americans with developmental disabilities as there are whites with those disabilities.

Policy Analysis:

Increases in funding for family support would better balance the funding for families willing to care for their young and adult children at home with the large amounts of money spent per person on developmental centers and community residential programs. It would also reduce the need for placement outside the home, a much more costly option.

There are two ways to increase that funding. Since family support is currently funded only by state dollars, it is eligible for a 100% match of federal dollars, raising its current $31 million to $62 million. The other alternative is to increase the state appropriation. DDD needs to decide on one or the other or a mixture of both. The decision needs to be made quickly before the Bush Administration succeeds in capping Medicaid,

- The Residential Waiting List

For a dozen years or more, the growing waiting list for community residential services has been used as the major indicator of unmet need for DDD services. The Arc of New Jersey and a few other advocates have used it to get policy-makers to provide more funding for group homes and some families have used it to assure that their children with developmental disabilities will live in them.

Although it has gone largely unnoticed, many organizations representing people with other kinds of developmental disabilities, such as spina bifida, cerebral palsy and epilepsy, have not lobbied for additional group homes. Their constituents don't want such restrictive community residential placements.

A critical analysis of the data available about the waiting list shows it to be a very inaccurate measure of unmet need. That should be obvious from the fact that DDD serves only about one fifth of the state's citizens with developmental disabilities, suggesting a much greater but unknown need.

There are other indicators of its inadequacy:

- The committee that prepared *The Plan to End the Waiting List by 2008* found that about 500 of the 2,500 then in the urgent category of the waiting list were *already* in DDD funded residential placements;
- 25% of families of those in the urgent category of the waiting list regularly turn down placement of their children when their turn comes up;
- In interviews conducted by NJIT, 75% all those on the waiting list said they viewed it as an insurance policy and weren't sure if they would accept placement if offered.

While many people on the waiting list are urgently in need of residential services, there is considerable evidence that many others are on it because of their ability to navigate the system. That further disadvantages those who don't know how to do that-those who are most likely to b poor and under-educated.

Despite these well-documented differences, DDD serves the same proportion of African-Americans as it does whites. In other words, it underserves African-Americans by 50%.

There are a number of historical and cultural reasons for this difference, including the fact that white middle- and upper-class parents have led and continue to lead efforts to increase services for children with developmental disabilities.

The results of this inequity are embedded in the structure of DDD and its services. A majority of its regional field offices are located in middleclass suburbs, some only accessible by car.

A majority of DDD clients in foster care, a less expensive and the least effective kind of community residential care are African-Americans. At same time they are significantly under-represented in group homes, the most expensive community residences.

DDD has instituted several culturally correct outreach efforts to inner-city African-Americans with limited success. Until it moves its services to where they live, advertises those services effectively and trains its staff to offer these clients services equal to those that whites receive, these efforts will yield little success.

Policy Analysis: The racial inequities in the distribution of DDD services can only be corrected if they are recognized by DDD staff at all levels and by state policy-makers who insist that their remediation be made a priority by DDD and who monitor DDD to assure that priority is met.

- Family Support

22,000 DDD clients are eligible for family support but 15,500 don't get any because of lack of funds. There has been no increase in funding for the last three years and none in next year's proposed budget.

22,000 of DDD's 33,000 clients live at home with their families but get only 6.7% of DDD's funding. Family support is the major service available to people who are not currently eligible for waiting-list services. The lack of those services often causes otherwise preventable problems that force them onto the waiting-list for much more expensive community placements.

DDD has a pilot project called 'Real Life Choices', which is only designed to support those in the urgent category of waiting list, primarily those whose families are willing to keep them at home. Its funding is dependent on increases in claiming matching funds from the federal Home and Community Based Services (HCBS) waiver and increases in fees charged to DDD clients who receive federal benefits to pay for basic living expenses. As yet, these expectations have not met projections and the rollout of the program is behind schedule.

Further, if an actual emergency arises, such as the incapacity or death of a caretaker, DDD regularly places the person with a developmental disability in the community or at developmental center.

Policy Analysis: The waiting list is an inadequate tool for measuring and ranking the urgency and severity of individual need and exacerbates many of the inequities now in the system. These flaws can only be remedied if DDD devises a procedure for prioritizing who gets which of its services that is based on effective measures of need and urgency in meeting that need.

New Jersey Compared to Other States

New Jersey has the highest income per capita of any state in the nation. Despite its wealth, it ranks in the bottom third of most indices that measure effective services to people with disabilities in the country.

For example, it ranks 30th in its over-all expenditures on people with developmental disabilities and 41st in expenditures on community services. The disparity is due to its heavy investment in developmental centers. It ranks 38th in its pay to state direct care staff working in developmental centers.

New Jersey ranks in the bottom fifth of states claiming federal reimbursement under the HCBS and other federal community Medicaid waivers. One study found that a quarter of DDD's budget was potentially eligible for additional federal matching funds. While DDD is currently revising its waiver efforts to bring in more federal match, its targets are lower than the quarter of a billion potentially available.

These are but a few of the examples revealed in federally funded studies that compare how all states serve their citizens with developmental disabilities

Policy Analysis: Unless DDD quickly maximizes its Medicaid claiming, it is likely to lose the opportunity to do so if the Bush Administration's attempts to cap each state's entitlements at existing levels succeed. This requires an immediate comprehensive review of all programs to determine if and how they can be restructured to increase claiming under the waivers.

When the current state budget crisis ends, the legislature should consider increasing DDD's funding to a level more appropriate to the state's high per capita income, so long as the additional funds are distributed equitably and effectively among those who need them.

Previous Attempts at Reform

Shortcomings in services to people with developmental disabilities and their families by DDD are chronic and have been public knowledge for two decades or more. During that

period, different elements of the developmental disabilities community have produced numerous reports calling for their remediation and several DDD directors have launched attempts to reform the system, the latest being 'Real Life Choices'.

None have succeeded thus far. They have failed for several reasons. Most were sabotaged by politically influential stakeholders who opposed them because they were detrimental to their interests as they saw them and because those stakeholders were not sufficiently involved in the development of the reforms.

The second major reason that reforms have failed is the culture of DDD itself. It is the largest division in state government that provides direct services, with about 8,000 employees, most of whom work in developmental centers. Until recently, most of its senior and middle management staff came from those centers and brought with them the top-down management style and low expectations of people with developmental disabilities common to those centers. Many are still promoted from those centers to DDD headquarters, which also has a history of centralized control and reluctance to delegate decision-making.

The third major reason is the failure of the developmental disabilities community as a whole to fully inform the Administration and the state legislature about the issues involved in the needed reforms and to enlist their support in achieving them. All too often, it has played one against the other for short-term gains that have disadvantaged people with developmental disabilities in the long run.

Policy Analysis: While the changes suggested in this paper are essential to begin to provide people with developmental disabilities and their families the services they need, there is no guarantee that they will occur. To do so will require strong informed leadership from the Governor's Office and willingness on its part to inform and involve the legislature in making the needed changes.

It will also require the Governor and the legislature to take on those who oppose closing developmental centers and to make it clear to the media and the public why those closings are central to improving and equalizing services to people with disabilities and their families. The current Administration is uniquely positioned for both tasks because of the acting Governor's close ties to the legislature and his announcement that he will not seek to continue in that office.

Finally, the success of these reforms will require time and continuity of political leadership. That leadership may depend on whether the acting Governor is succeeded by the nominee of his party. Continuity will require more active involvement on the part of the state legislators in the difficult policy decisions affecting people with developmental disabilities in New Jersey. If that involvement is not forthcoming, they will continue to fund services those people do not want or need.