

ADVOCATES FOR  
NEW JERSEY  
DEVELOPMENTAL CENTER  
RESIDENTS

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REPORT ON RESIDENTIAL CHOICE  
SURVEY

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**ADVOCATES FOR NEW JERSEY  
DEVELOPMENTAL CENTER RESIDENTS**

**REPORT ON RESIDENTIAL CHOICE SURVEY**

**EXECUTIVE SUMMARY**

The Supreme Court has found that Title II of the federal Americans with Disabilities Act requires that states serve persons with disabilities in community settings rather than in institutions only when three conditions are met: (1) the State's treatment professionals have determined that community placement is appropriate; (2) the transfer from institutional care to a less restrictive setting is not opposed by the affected individual; and (3) the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.

The State of New Jersey operates seven public intermediate care facilities for persons with mental retardation (ICF/MRs), also called developmental centers, as an option under its State Medicaid Plan. These centers serve more than 2,819 of New Jersey's most fragile citizens.

During the past several years, the New Jersey Division of Developmental Disabilities the state agency that oversees services for the Developmentally Disabled wherever they live, instructed its treatment teams to state that all current residents of developmental centers can live in community settings, thereby denying residents of the state run ICF/MR's their right to individualized treatment planning. As a result of this memo (Attachment A) the Division then stated "There are 2,457 individuals who have a recommendation for Community Placement in their IHP." (Attachment A1 "The Path to Progress," page 11). These statements give the misleading impression that community placement is an appropriate option for all residents of New Jersey's developmental centers. However, the Division has never surveyed parents, family members and guardians regarding their preferences for services and have disregarded the recommendations of those who directly provide for the care and treatment of those individuals

The "Advocates for New Jersey Developmental Center Residents" undertook a study of the opinions of developmental center residents' guardians and family members in order to determine treatment preferences. Three findings are made:

- (1) 96% of guardians and family members preferred continued ICF/MR services over community services;
- (2) the conduct of the Division of Developmental Disabilities in requiring treatment professionals to recommend community living, violates the requirement for individualized treatment planning; and
- (3) the use of state employees in the Bureau of Guardianship Services as "advocates" for persons receiving ICF/MRs services is a conflict of interest and should be suspended immediately.

The findings of this study suggest that ongoing investments will need to be made in order to maintain federal certification of New Jersey's ICF/MRs. In addition, the conduct of the Division who requires its treatment professionals to recommend community living violates the right for individualized treatment planning. Also, these recommendations do not consider the wishes of the individuals' family as the primary decisionmaker. This practice jeopardizes federal financial participation and should be suspended. Finally, the use of state employees in the Bureau of Guardianship Services as

“advocates” for persons receiving ICF/MR services is a conflict of interest and should be suspended immediately.

The Parents/Families Associations at each developmental center is pleased to offer its assistance to the Division in identifying family members and alternative guardians to address this need.

## **ADVOCATES FOR NEW JERSEY**

### **DEVELOPMENTAL CENTER RESIDENTS**

#### **REPORT ON RESIDENTIAL CHOICE SURVEY**

##### **BACKGROUND:**

The 'integration mandate' of the Americans with Disabilities Act requires public agencies to provide services "in the most integrated setting appropriate to the needs of qualified individuals with disabilities." In 1999, the United States Supreme Court affirmed the right of individuals with disabilities to live in their community in its 6-3 ruling against the state of Georgia in the case *Olmstead v. L.C. and E.W.*

The Court found that Title II of the federal Americans with Disabilities Act requires that states serve persons with disabilities in community settings rather than in institutions when three conditions are met: (1) the State's treatment professionals have determined that community placement is appropriate; (2) the transfer from institutional care to a less restrictive setting is not opposed by the affected individual; and (3) the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.

The high court upheld that mandate, ruling that Georgia's Department of Human Resources could not segregate two women with mental disabilities in a state psychiatric hospital long after the agency's own treatment professionals had recommended their transfer to community care.

The State of New Jersey operates seven public intermediate care facilities for persons with mental retardation (ICF/MRs), also called developmental centers, as an option under its State Medicaid Plan. In choosing to do so, New Jersey is required to offer ICF/MR services to all Medicaid-eligible individuals who qualify for services. The hallmark of ICF/MR level of care is Active Treatment. Active Treatment refers to aggressive, consistent implementation of a program of specialized and generic training, treatment and health services. Active Treatment does not include services to maintain generally independent clients who are able to function with little supervision or in the absence of a continuous Active Treatment program. (42 CFR 483.440(a))

Each client in an ICF/MR receives an annual program plan, called an Individual Habilitation Plan (IHP), which serves as a guide to treatment planning. In contrast, services in community settings funded by the Home and Community-Based Waiver are not required to meet the Active Treatment standard. In many instances the individuals living in group homes or other settings under the Home and Community Based Waiver (HCBW) do not even have an IHP as seen in recent audits of DDD contracts.

#### STATEMENT OF NEED:

The overwhelming majority of the families and guardians of individuals receiving ICF/MR services are concerned that the New Jersey Division of Developmental Disabilities has embarked on a process which will result in its meeting the three Olmstead criteria for all persons currently receiving ICF/MR services but without attention to their continued need for individualized treatment services (Active Treatment program).

#### Fundamental Alteration:

Over the past ten years, the New Jersey Division of Developmental Disabilities has expanded the capacity of the Home and Community-Based Waiver. However, most of this new capacity has been given to moving current residents of developmental centers into the community. In fact, during the past 10 years the number of persons receiving ICF/MR services in New Jersey has decreased by about 1,000. At the same time, however, the Division did not make any significant headway in addressing the lengthy waiting list for waiver services among persons with developmental disabilities living in the community. During the same period, the waiting list has grown to more than 5,000 persons. This practice creates tension between families of individuals living in ICF/MRs and those on the waiting list for community services.

#### Treatment Professionals:

In 2001, the New Jersey Division of Developmental Disabilities instructed treating professionals in its developmental centers to include a statement in each client's individual habilitation plan that the resident could be served in the community. The only exceptions to this statement were for individuals who are considered dangerous to others (by virtue of having a criminal record) or individuals who could verbalize their desire to remain in their placement. Having exterminated independent professional judgment at its developmental centers, the Division promulgates the belief that no treating professionals support continued placement in an ICF/MR. In its publication "The Path to Progress, page 11" the Division notes "There are 2,457 individuals who have a recommendation for Community Placement in their IHP." Obviously, this statement reflects the influence DDD has to advance their agenda by ignoring the federal requirement for individualized treatment planning and family choice.

#### Consent of the Individual:

Many individuals living in New Jersey ICF/MRs do not have family guardians and are instead, served by employees of the New Jersey Division of Developmental Disabilities through the Bureau of Guardianship Services (BGS). As per instructions from the New Jersey Division of Developmental Disabilities, individuals served by BGS

and those without a guardian were listed as not opposing community placement in their IHPs regardless of level of need or mental capacity. See Attachment A

In fact, within the last two years, the Division changed the IHP documents to further push the alleged community preference. The IHP was changed to a person centered plan (PCP), a planning document now written in first person language. The PCP contains a template for language expressing such a choice so that all of the PCPs read the same. As a result, the PCPs contains an explicit statement of the client's preference in what appears to be the client's own words, for community or ICF/MR services, regardless of whether the client has been deemed competent to makes such a determination. In reality, many of the clients who have allegedly made statements regarding their preference are non-verbal or unable to make such a determination. This procedure is coercive and denies guardians of their legal right to make treatment decisions on behalf of their loved ones.

Based on these changes in state policy some community advocates with the tacit support of the Division, have argued that the entire population of individuals served in ICF/MRs, that is more than 2,400 individuals, is being inappropriately served through the program and that, as a result, all ICF/MRs in New Jersey should be closed. In direct contrast, many parents and guardians oppose community placement, and believe that the ICF/MR continues to be the most appropriate setting for providing care to their loved ones. There was a petition distributed to the friends and families of the residents of the Hunterdon Developmental Center in late 2006. Over 2,300 signatures were collected, bound and presented to the Governor and State Leaders indicating their overwhelming opposition to the forced removal of residents from the Developmental Centers and a request for legislation that would review the policies of DDD and resume admissions to the centers when the individuals needs required the level of care available only at an ICF/MR (SEE Attachment B).

Unfortunately, no survey of guardians and family members has ever been undertaken by the Division and requests to read the IHP or PCP documents to see what the family's preferences are, have been ignored. The current proposals to move all developmental center residents into the community do not take into account the actual level of services required for each individual. This in turn represents a challenge to policy makers and state government because they cannot adequately determine the level of financial support required to provide an appropriate level of funding for New Jersey ICF/MRs nor to those who will be moved when federal transition dollars disappear under the Money Follows the Person. MFP dollars are federal dollars that increase an individuals budgets for 12 months after leaving and ICF/MR. The Center for Medicare and Medicaid (CMS) requires the states assurance that those dollars will be available through state resources one the federal dollars expire.

This study represents the first systematic effort to assess the opinions of guardians and family members regarding the need for ICF/MR services in New Jersey.

#### METHOD:

Each of the seven ICF/MRs operated by the State of New Jersey maintains an active parents/family group. In order to ascertain the preference of parents and non state guardians for ICF/MR versus community services, the presidents or representatives for each parent/family group convened a Task Force to conduct a survey of all parent and non state legal guardians of residents at the centers. The Task Force, named Advocates for Developmental Center Residents, designed a survey with a single question: "Are you in favor or opposed to community placement for your loved one?" The survey was mailed to all of the families at six of the seven centers, which comprised the membership of the parent/family group at each facility (Attachment D1 and D2). The seventh center, Woodbine Developmental Center was unable to participate due to the failing health of their parent/family group leadership. The center would not allow the Task Force to prepare the mailings in an effort to protect confidentiality.

The Task Force contacted Kim Friend, Director of the Bureau of Guardianship Services with a request to send the survey to the state-employed workers at BGS in an attempt to have state-appointed guardians participate in the process. As of the writing of this report she has not responded.

Funding for the mailing was obtained through donations from the parent/family group associations.

#### RESULTS:

Data were collected from parents and guardians at six of seven facilities. We will revise this report when data for the Woodbine Developmental Center are collected.

Results show survey responses are overwhelmingly in favor of continued ICF/MR (developmental center) services (Table 1). We received a total of 1,417 responses. Of these, 1,359 responses are in support of continued ICF/MR services and 58 responses are in favor of community placements and services through the HCBW. In percentage terms, this represents 96% in support of continued ICF/MR services and only 4% in favor of community placements.

Table 1: Overall Preferences for Service Type by Developmental Center

<u>Developmental Center</u>	<u>ICF/MR</u>	<u>HCBW</u>	<u>Total</u>
Hunterdon	508	8	516
New Lisbon	205	13	218
Green Brook	64	1	65
Woodbridge	240	15	255
Vineland	158	10	168
North Jersey	184	11	195
Total	1,359	58	1,417
Percent	96%	4%	100%

Table 2 shows the “as received” data by status or relationship to the center residents. The status category with the highest response is guardian followed closely by those who did not give their relationship status. Although many respondents did not fill in their relationship information, the center representatives know that many of the respondents are in fact, parents and legal guardians. However, no data are altered to reflect what we know to be the case. These responses remain listed as “not given”.

Table 2: All Responses by Relationship Status

<u>Developmental Center</u>	<u>Totals</u>	<u>Family</u>	<u>Parent</u>	<u>Guardian</u>	<u>Not Given</u>
Hunterdon	516	59	56	217	184
New Lisbon	218	65	17	77	59
Green Brook	65	32	1	15	17
Woodbridge	255	14	31	116	94
Vineland	168	8	7	69	84
North Jersey	195	22	14	66	93
Total	1417	200	126	560	531
Percent	100%	14%	9%	40%	37%

The 1,417 responses are also tabulated for each choice by relationship status. Table 3A shows responses in favor of ICF/MR services by family, parent, guardian, and “not given”. Table 3B shows responses in favor of HCBW services by family, parent, guardian, and “not given”. The breakdown of responses by relationship status in Table 3A is similar to that of Table 2 with the highest response again by those identifying themselves as guardians. In contrast to those in favor of ICF/MR (Table 3A), those in favor of HCBW were more reluctant to list their relationship (53% “not given”) to the developmental center resident (Table 3B).

Table 3A: Responses in favor of ICF/MR by Relationship Status

<u>Developmental Center</u>	<u>FAMILY</u>	<u>PARENT</u>	<u>GUARDIAN</u>	<u>NOT Given</u>	<u>Total</u>
Hunterdon	61	55	207	185	508
New Lisbon	58	17	75	55	205
Green Brook	28	1	15	17	61
Woodbridge	16	29	110	88	243
Vineland	8	7	65	78	158
North Jersey	21	12	67	84	184
<b>Total</b>	<b>192</b>	<b>121</b>	<b>539</b>	<b>507</b>	<b>1359</b>
<b>Percent</b>	<b>14%</b>	<b>9%</b>	<b>40%</b>	<b>37%</b>	<b>100%</b>

Table 3B: Responses in favor of HCBW by Relationship Status

<u>Developmental Center</u>	<u>FAMILY</u>	<u>PARENT</u>	<u>GUARDIAN</u>	<u>NOT Given</u>	<u>Total</u>
Hunterdon	0	2	3	3	8
New Lisbon	7	0	1	5	13
Green Brook	1				1
Woodbridge	1	2	5	7	15
Vineland	0	0	4	6	10
North Jersey	1	1	0	9	11
<b>Total</b>	<b>10</b>	<b>5</b>	<b>13</b>	<b>30</b>	<b>58</b>
<b>Percent</b>	<b>16%</b>	<b>8%</b>	<b>23%</b>	<b>53%</b>	<b>100%</b>

The largest number in this Table again is for “not listed” with guardians coming in second.

In Table #4 we looked at the number of clients at each center as stated on the DDD website census as of 3/31/09 and compared that number with the number of responses we received. We also asked for the total of those in each center under Bureau of Guardianship Services along with the number of those who had recommendations for ICF/MR vs. HCBW. We received no response to our request for their preferences for those they represent and received only the total number of clients under the BGS from the Division of Developmental Disabilities. DDD told us they did not have the number of guardians shared by this group or the recommendations that the BGS staff had made for placement.

Table 4

FACILITY	CENSUS	#OF RESPONSES
GREENBROOK	91	65
HUNTERDON	561	516
NEW LISBON	432	218
NORTH JERSEY	403	195
VINELAND	441	168
WOODBINE	487	non participant
WOODBIDGE	404	255
<b>TOTAL</b>	<b>2819</b>	<b>1417</b>
TOTAL OF CLIENTS UNDER BGS	1184	
Total of all participating centers	<b>2,332</b>	

As you can see in Table #4 the total census of our 6 participating centers is 2,332. It shows that our response based on that census is 61% of the total. We did not receive a break out of the BGS clients by center as DDD does not have access to that database and BGS director Kim Friend did not respond to our requests. We do believe that there are families that are very involved with their loved ones at the center but may have turned over legal guardianship to the Bureau of Guardianship services so that they might ensure that their loved one was taken care of according to their wishes when they were gone.

## CONCLUSIONS:

The study findings illustrate that continued ICF/MR services is the preferred service modality for the vast majority of individuals currently being served in New Jersey Developmental Centers. Nearly 96% of those responding to a survey stated that they preferred the services available at State-operated developmental centers to those available in the community through the Home and Community Based Waiver.

The results of our simple survey show that families/representatives of those living in our Developmental Centers are happy with the care and life that their loved ones have and are opposed to any movement into the community.

The Division has promoted the myth that more than 2,400 residents can move to the community over a number of years while ignoring the statements within the treatment plans where the families' wishes are expressed. The families have been treated as if they do not understand the services that their loved ones need by the language in the Path to Progress of DDD. It is our hope that this survey will demonstrate to the public and our elected officials that the wishes of the primary decision makers have been systemically ignored. The truth is that by an overwhelming majority, parents and representatives of those who live in our NJ Developmental Centers are happy with the care and life provided for their loved ones and that choice should be respected and preserved. We also hope that an informed public will lead to an opening of doors to our centers. We watched as many of the center residents without family guardians were being moved out of the centers. Many did not fare well and came back to the centers or transferred to nursing homes. Clients that returned to the centers they came from often returned due to deteriorated health conditions and complications. The Division has declined to release the number of those who left the centers, were moved from group home to group home, sometimes to nursing homes and even sent back to a Developmental Center although often not the one they came from. This information along with a 10 year anniversary look at the number of deaths that have occurred since the closure of North Princeton Developmental Center are necessary to understand the fact that one size will not fit all in terms of placement and level of service.

For the last few years the Division of Developmental Disabilities has hired an outside agency to come into the centers and look for candidates for movement into the community. They are moving people out with big budgets under FMAP short term funding that will not last after the first 12 months. The people leaving now are more disabled than those who left in previous years when they were determined to no longer need the ICF/MR level of care. These recent clients had extensive needs that the community was not and still is not prepared for.

Families once again tried to get someone to listen. Instead a NJ Assemblyman Louis Greenwald came up with a plan to close the homes where our children live. At his press conference he had no one with him representing any of the Parent/Family Groups from the Centers. He had at the time of his press conference never even visited a Developmental Center!

Family representatives from all seven Developmental Centers decided the only way to bring light to the issue was to do a survey of our own regarding their choice. By doing a survey we were hoping to dispel the myth of the 2400 and keep the innocents from being put in harms way. We also hope that an informed public will lead to an opening of doors to our centers, enabling others of obtain this level of care if their loved ones need it.

#### RECOMMENDATIONS:

The findings of this study demonstrate the continued demand for services from New Jersey's public developmental centers. Given that ICF/MR level services are covered under the State Medicaid Plan and rise to the level of an entitlement, continued investment in these services will be necessary in order to ensure that these centers continue to remain certified by the Centers for Medicare and Medicaid Services (CMS) and, therefore, continue to generate federal financial participation (FFP).

However, the recent conduct of the New Jersey Division of Developmental Disabilities has placed these funds at risk in two respects.

First, the Division has mandated that clinical teams include a statement in client IHPs and/or PCPs that each and every resident could be served in the community. This practice represents a clear conflict of interest. Use of such a blanket statement also deprives current ICF/MR clients of their right to individualized treatment recommendations. Such a systemic deprivation of these rights places federal funding at risk. The Division must suspend its guidance to treatment professionals and allow them to make independent decisions consistent with the scope of their professional practice and judgment.

Second, the unwillingness of the Bureau of Guardianship Services to participate in this survey, combined with public statements by the Division that all residents of New Jersey's ICF/MRs "have a recommendation for Community Placement in their IHP," suggests that the rights of the individuals served by BGS are being violated. The functional needs of the clients served by the Bureau are no different than those served by family guardians. However, the conduct of the Division suggests that these individuals will be the first to move to the community because their state-employed guardians do not function independently of the Department of Human Services. This also is a clear conflict of interest. It is recommend that the Division undertake an effort to secure family guardians for these individuals and, failing this, appoint independent, volunteer, third parties to undertake the responsibility of becoming guardians for these individuals. The Parent/Family Associations at each Developmental Center would be pleased to support the Division in this work.

## **The timeline of events leading to the myth of the 2400.**

As of 2001 ALL IHP documents contained a statement that the person was eligible to live in the community based on the memo and not on the needs. Hence the myth of the 2,400 was born (Attachment A).

The Division of Developmental Disabilities and several provider agencies began to state that 2,400 people "wanted to leave the Developmental Centers". The myth grew.

Many attempts were made to get this matter corrected. Parent groups and individual parents and guardians asked to have the myth corrected. It was known by DDD that the number was not a true number and Division staff and leadership admitted it to Parents from the Developmental Centers but did nothing to publicly disprove the myth.

In 2006-2007

Members of the Association for Hunterdon Developmental Center along with their families friends and neighbors signed a petition regarding choice. The mailing only went to those families from Hunterdon Developmental Center and yet we collected over 2,300 signatures asking the legislature in New Jersey to investigate the forced removal of clients from the centers. The petition also asked the NJ Legislature to create a bill to prevent to closed admission policy at the centers and to prevent the closure of any centers without a full hearing and vote of the entire NJ Legislature. The petitions were delivered twice to Governor Corzine (once in person), and to State Leaders but no action was taken (Attachment B).

The Division held hearings in the winter of 2007 in compliance with Senate Bill 1090 a bill that wanted to know more about the activities of the Division of Developmental Disabilities and see more transparency. Hearings were part of that bill and parents and family members were hopeful that now they could be heard and their choices for their loved ones respected.

The hearings were in fact posted as an attempt to hear from families with loved ones at the Developmental Centers and yet the original proposal had none of the four hearings at a Developmental Center. This was in the month of January and in the end two of the sessions were held at DC's and two were held at Community Colleges that were nowhere near any centers. The comments from families and relatives were overwhelming against movement from the Centers and hundreds of written comments demanding transparency in movement recommendations and a request that "real" IHP processes must be restored immediately. The testimony and written documents should be reviewed. Attachment C-letter sent or read at the hearings. The total number of those letters received is unknown. Transcripts of these hearings are available upon request.

The Division of Developmental Disabilities ignored those who attended and wrote their comments. The Path to Progress, which was the supposed result of these hearings in no way, reflects what the families wanted. Again the Division continued to refuse to publicly acknowledge the number of families against movement from the centers. They put a plan in place to hire agencies to assist in that movement of the innocents. The agencies that were awarded those contracts had no track record. On page 11 of the Path to Progress it states that "There are 2,457 individuals who have a recommendation for Community Placement in their IHP" (Attachment A1). This is due to the memo of 2001 ordering all documents to say the person was eligible not based on level of care, choice or need. This false number was again being used to achieve an agenda and not to care for those among the Developmentally Disabled who are the most vulnerable.

# ATTACHMENT A

## HUNTERDON DEVELOPMENTAL CENTER

### Meeting Individual Needs and Maximizing Growth Through Training

**DATE:** January 12, 2001  
**TO:** HPCs  
**FROM:** Emil G. Brisson, DPD *EB*  
**SUBJECT:** Data on Eligibility for Community Placement

The Division of Developmental Disabilities has requested that we provide information on eligibility of clients for community placement and agreement/opposition of families/guardians to community placement.

The following information will need to be provided to MIS for each client, following his/her annual IHP meeting:

1. Did the individual request a community placement? Yes/No/Unable to express
2. Did the family/guardian oppose a community placement? Yes/No
3. Did the BGS guardian oppose community placement? Yes/No
4. Did the IDT determine the individual eligible for a community placement? Yes/No
5. Date of annual IHP meeting where this determination was made.

In regard to question number 2, if the client has neither family nor guardian, the question should be answered No.

In regard to question number 3, if the client has a private guardian or no guardian the question should be answered No.

The IHP date requested in question number 5 is the current annual IHP date, not the date the client was first found eligible.

*Handwritten note:* Please refer to the attached letter to the Division of Developmental Disabilities dated 1/12/01.

In regard to question number 4, clients should be considered eligible for community placement unless they represent a serious danger to others. Clients would be considered to be represent a serious danger to others for the following reasons: clients with charges pending in a court of law, Class I Commitment, Incompetent to Stand Trial (IST), criminal convictions, determined Not Guilty by Reason of Insanity (NGRI), or Adjudication of Delinquency. At this time, none of the clients at HDC fall into any of these categories. If an IDT determines that a client should not be eligible for community placement because he/she presents a serious danger to others for a reason other than one of the above, the

## ATTACHMENT A

HPC must provide written justification (in the IHP Addendum) and this justification will be reviewed by the HPC's supervisor before the IHP goes for typing.

This is a change from our previous procedure of having the IDT identify if a client may be ready for a community program and should be assessed by Community Services. In 2000, funding was provided to place 144 clients from Developmental Centers into community placements. The Division expects that there will be more funding available in the future for Developmental Center clients to move to community residences. Collecting this data will help the Division plan for future initiatives. It should be stressed that, just because an IDT identifies a client as eligible for community placement, it does not mean that the Division will start looking for a community placement. At this point, only 144 Developmental Center clients are funded for community placement and those clients have been identified and their families have agreed to consider proposals that have been submitted. Also, at this time, the Division is not placing Developmental Center clients in the community if their families are opposed to the placement.

MIS will be providing forms for HPCs to provide this information. We are required to provide this information for all clients, beginning with IHP meetings after January 1, 2001. For IHP meetings that have already taken place in January, HPCs should review these clients at another meeting in January. We will distribute the forms from MIS as soon as we receive them. Completed forms should be returned to Joanne Wright within 5 working days after the meeting.

You should not document in the Addendum that the IDT has determined the client eligible for community placement. At the February 9 Program Assistants meeting, we will be discussing this and will formulate wording for this.

This process will be implemented immediately.

C: W. A. Wall  
L. Cronce  
G. C. Butherus  
J. Smith  
C. Taylor  
K. Blazek  
D. Spinks  
B. Iovovich, MD  
E. Blackwood  
R. Blankenberg, Ph.D.  
R. Schumacher  
E. DellaSala  
J. Simonetta  
P. Sethi  
S. Vivenzio  
File

## ATTACHMENT A1

Kentucky, North Carolina and Minnesota's criteria are similar to New Jersey's i.e.:

(a) The treatment professionals determine that an SCL placement is appropriate for the individual; and

(b) The SCL placement is not opposed by the individual or his or her legal representative.

### C. Characteristics of Individuals in Developmental Centers

The Developmental Disabilities Planning Institute (DDPI) at the New Jersey Institute of Technology (NJIT) conducted an assessment of all individuals (over 3,000 people) living in New Jersey's seven developmental centers (DC). The original assessment instrument used with a large sample of people living in the DCs in 2000/2001 was modified after consultation with key staff of the Division, including senior level and program people from each DC. Informants in eight programmatic areas at each DC who knew each person well were trained in the use of the instrument and completed that module specific to their programmatic area. The programmatic areas were Social Work, Psychology, Physical Therapy, Occupational Therapy, Habilitation, Nursing, Nutrition, and Speech. Assessments were completed in late spring of 2006. The assessment instruments are in Appendix \_\_\_\_\_.

The assessment provides the Division with:

- a. A standardized tool for use by all developmental center staff members to describe the unique abilities and needs of each resident;
- b. A statewide database which includes information regarding the abilities, preferences and support needs of each resident of the developmental centers; and,
- c. The information necessary to identify specific obstacles which may influence the decision-making of staff members who determine, in the Individual Habilitation Plan (IHP), the potential for an individual's community placement.

### Assessment Process Findings

#### a. Number of Targeted Individuals

A successful transition process includes a number of key steps. The first and perhaps most critical is for the individual and their guardian to make an informed choice. There are **2,457 individuals who have a recommendation for Community Placement in their IHP**. This is about 81% of the people living in the developmental centers. **Of these 2,457 individuals, 2,303 individuals do not oppose community placement.** As such, the Division will be planning for

## ATTACHMENT A1

placement of 2303 individuals. This is about 75 % of people living in the developmental centers.

The Division's experience has been that transition to community placement is most successful when the transition process is supported by the individual's family members. A strong support system is formed for these individuals. It is for this reason that the Division has decided to place those with family support in the community first. When family/guardian support is factored in the number of individuals ready to begin the transition process is reduced. Of the remaining 2,303 individuals, the family/guardians opposed an individual leaving the center in 1,298 cases, even though the IDT and the person did not oppose moving. Further, from the legal point of view, it is unsettled in this State whether a guardian has the legal ability to keep an individual in a developmental center despite the individual's interest in community placement.

There are **1,005** individuals whose family/guardians do not oppose community placement. This group will be prioritized to make the transition to community residences first. DDD will begin the independent support coordination process with these individuals.

The success of a community placement can depend on the support and involvement of the person and the individual's family members. DDD has done considerable work in preparing families of people living in institutions to evaluate community options. DDD contracted with the UMDNJ School of Public Health to assist in the preparation of families by providing information and relaying family concerns to DDD. UMDNJ's Developmental Disability Family Education Project will continue to provide support to all 2,457 individuals and their families/guardians. Emphasis will be placed on the 1,298 families/guardians that do not support community placement at this time. This support and education will ensure they gain an understanding of the services and supports available in the community. This will provide families with the information they require to adequately support their family member through informed choice about transition.

The Division has chosen to work with the 1,005 people where the IDT, person and family do not oppose moving from the center first. This approach seems most feasible given the need to expand community infrastructure to accommodate this first group of people. The Division is committed to serving individuals in the least restrictive setting while providing safety and protection from harm. A reasonable pace of community placements from the developmental centers must be established, while ensuring that supports and services are available before moving forward. In reviewing the supports and services required for first 1,005 people, many individuals require high level support needs. Individuals determined to have medium or high self care needs requiring assistance with virtually all self care activities such as personal hygiene, household chores and community activities comprise 69.9 % of the group. About 64.1% have medical needs which require specialized staff training (not a nurse). Approximately 76.4 % of the people have severe behavior needs that require a formal behavior plan (43.2%) or have behaviors that are extremely high risk to themselves or others (33.2%).

**PETITION TO PRESERVE CHOICE**

1-8-07

<p>Petition summary and background</p>	<p>We the undersigned are opposed to the forced removal of residents from NJ Developmental Centers without the promise of the continuation of their current levels of support for the long term. We also oppose the admissions policy for our Developmental Centers that prohibits those who are eligible for ICF/MR services from knowing of, or receiving that placement option.</p>	<p>We, the undersigned, are concerned citizens who urge our leaders to act now to review the current methods, policies and procedures regarding those currently residing in our Developmental Centers, and those needing, but not now receiving, care in a NJ Developmental Center. We ask the legislature to consider the passage of a bill that would prohibit the closure or change of purpose of any Developmental Center without an act of the legislature. We also ask that a representative group from the leadership of the parent groups from the centers meet directly with the Governor to discuss the matters mentioned above.</p>
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Printed Name	Signature	Address	Comment	Date
[REDACTED]	[REDACTED]	[REDACTED]	We oppose the forced removal	12/27/07
[REDACTED]	[REDACTED]	[REDACTED]		
[REDACTED]	[REDACTED]	[REDACTED]		
[REDACTED]	[REDACTED]	[REDACTED]		
[REDACTED]	[REDACTED]	[REDACTED]		
[REDACTED]	[REDACTED]	[REDACTED]		
[REDACTED]	[REDACTED]	[REDACTED]		
[REDACTED]	[REDACTED]	[REDACTED]		
[REDACTED]	[REDACTED]	[REDACTED]		

**SAMPLE**

# ATTACHMENT C

TESTIMONY FOR DDD HEARINGS

DATE \_\_\_\_\_ LOCATION \_\_\_\_\_

NAME \_\_\_\_\_

ADDRESS \_\_\_\_\_

PHONE NUMBER AND E-MAIL  
ADDRESS \_\_\_\_\_

I am here today to tell the Division of Developmental Disabilities and the Department of Human Services that these hearings are simply an effort to comply with S1090. They are not in any way going to result in a system that represents our wishes and desires for our family members. The Division of Developmental Disabilities has already circumvented this process and as we speak is planning the removal of over 40 persons from their homes in our Developmental Centers this year alone with many hundreds to come over the next several years. I want to tell the Commissioner that these people are our most vulnerable citizens and to force state employees to say in IHP documents that they can live in the community is in violation of their rights to receive the services and supports that can give them a full, safe and happy life. I am demanding that all efforts to remove persons from the Developmental Centers who do not have a family member to provide consent and oversight be immediately stopped until a transparent system is in place for everyone. In addition, I demand that our IHP documents represent the true needs of our family members and not the philosophical rhetoric of the Division of Developmental Disabilities. This will allow the "myth of the 1500" to end and real planning for the future to begin.

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P.O. Box 59  
Avenel, NJ 07001

March 22, 2009

ATTACHMENT D1

Dear Family Member or Guardian of a WDC Resident,

**YOUR IMMEDIATE RESPONSE IS NEEDED!**

I am sending you the enclosed postcard which needs your input. Over the last 8 years the Division of Developmental Disabilities (DDD) has aggressively and purposely overstated stated the number of individuals residing in developmental centers who want community placement.

While we realize that some families may be currently seeking community placement, we believe that the majority of families feel that their loved ones are best and appropriately served in their current home at Woodbridge Developmental Center.

Members of Hunterdon, New Lisbon and Woodbine Developmental Centers Parent and Family Associations are also being asked to fill out these postcards and send them back as soon as possible. Together, we are attempting to get a more accurate count so that the "myth of the 2,400" requesting community placement will finally be dispelled. We would like to show that plans to downsize and/or close the developmental centers are not based on what our families want.

Please fill out the enclosed card today and answer the question based on your choice! Even if you are not the legal guardian, you still have a voice.

Thank you for your prompt attention to this very important matter.

Respectfully,



Joanne R. St. Amand, President  
WDC Parents Association

[irst.amand@verizon.net](mailto:irst.amand@verizon.net)  
(H) 908-272-0399  
(W) 732-205-5257

# ATTACHMENT D2

3/2009

## NOTICE OF RESIDENTIAL CHOICE

PRINT YOUR NAME \_\_\_\_\_

I AM THE GUARDIAN/PARENT/FAMILY MEMBER  
(please circle all that apply)

OF \_\_\_\_\_ who is currently living  
RESIDENT'S FULL NAME

at \_\_\_\_\_  
DEVELOPMENTAL CENTER NAME

*Check only one of the following:*

\_\_\_\_\_ I am **OPPOSED** to community placement for my family member/ward.

\_\_\_\_\_ I am in **FAVOR** of community placement for my family member/ward.

*If at any time in the future my decision changes, I will notify you in writing.*

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Daytime phone number                      Email address

Full Address (Please print clearly):

Street: \_\_\_\_\_ Unit # \_\_\_\_\_

Town/City: \_\_\_\_\_

State: \_\_\_\_\_ Zip Code: \_\_\_\_\_

3/2009

## NOTICE OF RESIDENTIAL CHOICE

PRINT YOUR NAME \_\_\_\_\_

I AM THE GUARDIAN/PARENT/FAMILY MEMBER  
(please circle all that apply)

OF \_\_\_\_\_ who is currently living  
RESIDENT'S FULL NAME

at \_\_\_\_\_  
DEVELOPMENTAL CENTER NAME

*Check only one of the following:*

\_\_\_\_\_ I am **OPPOSED** to community placement for my family member/ward.

\_\_\_\_\_ I am in **FAVOR** of community placement for my family member/ward.

*If at any time in the future my decision changes, I will notify you in writing.*

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Daytime phone number                      Email address

Full Address (Please print clearly):

Street: \_\_\_\_\_ Unit # \_\_\_\_\_

Town/City: \_\_\_\_\_

State: \_\_\_\_\_ Zip Code: \_\_\_\_\_

FINAL NOTE: We thank all of those who returned their choice survey postcard and those who compiled all the data that was collected to generate this report. Our hope is that we can finally understand that the majority of those who are living at the developmental centers are happy in their homes and need to have their choices acknowledged. There is no mandate to close any centers in any law including the Supreme Court decision in the Olmstead case. The representatives of those living in our developmental centers should be respected in the same way that those who represent those living at home or in other community placements are afforded.

Thank You!

# Results of Residential Choice Survey Letter

Submitted to

Task Force on the Closure of the State Developmental Centers

April 24, 2012

From

Joanne R. St. Amand

## Woodbridge Developmental Center Parents Association

This document contains the responses of a survey letter sent to the family and / or private guardians of 303 residents of Woodbridge Developmental Center during the week of April 2, 2012. This survey was conducted to show the residential choice of family and private guardians and also validate the results of the survey on residential choice conducted by Advocates for Developmental Center Residents, March, 2009. Copies of the March 2009 report were provided to each Task Force member by Cindy Bartman, President of the Association for Hunterdon Developmental Center as extended written testimony during the March 26, 2012 Task Force Hearing.

The results of this survey indicate the overwhelming majority again choose the developmental center over community placement and are consistent with the results of the 2009 survey. Specifically ~~199~~ <sup>210</sup> out of ~~207~~ <sup>218</sup> families and / or guardians of WDC residents or 96% are opposed to community placement.

Survey	Surveys Mailed	Returned Responses	In favor of Community Placement	Opposed to Community Placement	Percent Opposed to Community Placement
<b>This Survey</b>	<b>303</b>	<b>209</b> <sup>217</sup> <sup>218</sup>	<b>8</b>	<b>201</b> <del>209</del> <sup>210</sup>	<b>96%</b>
March 2009	404	255	15	240	94%

Included in this document are <sup>26</sup> ~~27~~ letters, e-mails and notes supporting continued developmental center (ICF/MR) services, copies of 8 signed letters in favor of community placement and <sup>209</sup> ~~199~~ <sup>210</sup> signed letters opposing community placement.

Respectfully submitted,

Joanne R. St. Amand  
Woodbridge Developmental Center Parents Association  
E-mail: jrst.amand@verizon.net

Updated 4/29/12 ~~7/27/12~~ 8/2/12