State of New Jersey

Department of Human Services

North Jersey Developmental Center Initial & Year Two Closure Report

NJ DHS Office of Research, Evaluation & Special Projects
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Commissioner

Table of Contents

Introduction

In 2006, the New Jersey State Legislature required the New Jersey Department of Human Services' (NJ DHS) Division of Developmental Disabilities (DDD) to "develop a plan with established benchmarks to ensure that within eight years of implementation, each resident in a State developmental center who expressed a desire to live in the community and whose individual habilitation plan so recommends, is able to live in a community-based setting."[1] In 2007, DDD introduced its "Path to Progress" plan,[2] detailing the course by which residents of State Developmental Centers (DCs) who wanted to live in the community could do so.

In 2011, a new statute created a five-person "Task Force on the Closure of State Developmental Centers" with members empowered to review all of the DCs and to make binding closure recommendations. In July 2012, the Task Force voted to close North Jersey and Woodbridge Developmental Centers within five years.[3] North Jersey Developmental Center closed on July 1, 2014; Woodbridge Developmental Center closed on January 9, 2015.

Subsequently, in January 2016, a law[4] was enacted requiring the NJ DHS to "conduct or contract for follow up studies of former residents" of North Jersey Developmental Center and Woodbridge Developmental Center who transitioned into the community after August 1, 2012 as well as others who were placed in the community as a result of plans to close another State developmental center.[5]

Through this legislation, the Commissioner of the Department of Human Services is required to submit reports from these studies to the Governor and the Legislature on an annual basis for each of five years following the closure of both developmental centers.

This report presents data for the first two years following the closure of North Jersey Developmental Center.[6] When possible, data points are reported separately for each period but, in some cases (for example, data that were drawn from surveys completed only at the end of year 2), data for years one[7] and two are collapsed into one data point. This report addresses the topics mandated in legislation focusing on persons, settings, services and outcomes. Contextual comparisons as feasible and appropriate are made between individuals who moved

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[1] See http://www.njleg.state.nj.us/2006/Bills/S1500/1090_R1.PDF

[2] http://nj.gov/humanservices/ddd/documents/Documents%20for%20Web/Olmstead/JSOlmPlanFinal.pdf

[3] The Task Force's final report is available at: http://www.state.nj.us/humanservices/ddd/documents/Documents%20for%20Web/Closure%20Task%20Force%20Report.pdf

[4] A-1098/S-671 (Vainieri Huttle, Eustace, Diegnan, Giblin/Pou, Sarlo, Weinberg). See: http://www.njleg.state.nj.us/2014/Bills/PL15/197_.PDF.

[5] Or State psychiatric hospital.

[6] Ideally, analysis would be conducted annually. However, data from two years was needed for North Jersey because the legislation was enacted the year after North Jersey closed (see Figure 1).

[7] Year one is actually from August 1, 2012 through June 30, 2015, one year following NJDC's closure.

into community placements and individuals who moved into other developmental centers. Information was obtained from many sources and utilized varied methodologies including consumer and family surveys, specialized data collection instruments, and multiple databases from the DDD, the Division of Medical Assistance and Health Services[8] (DMAHS), and the Division of Mental Health and Addiction Services (DMHAS).

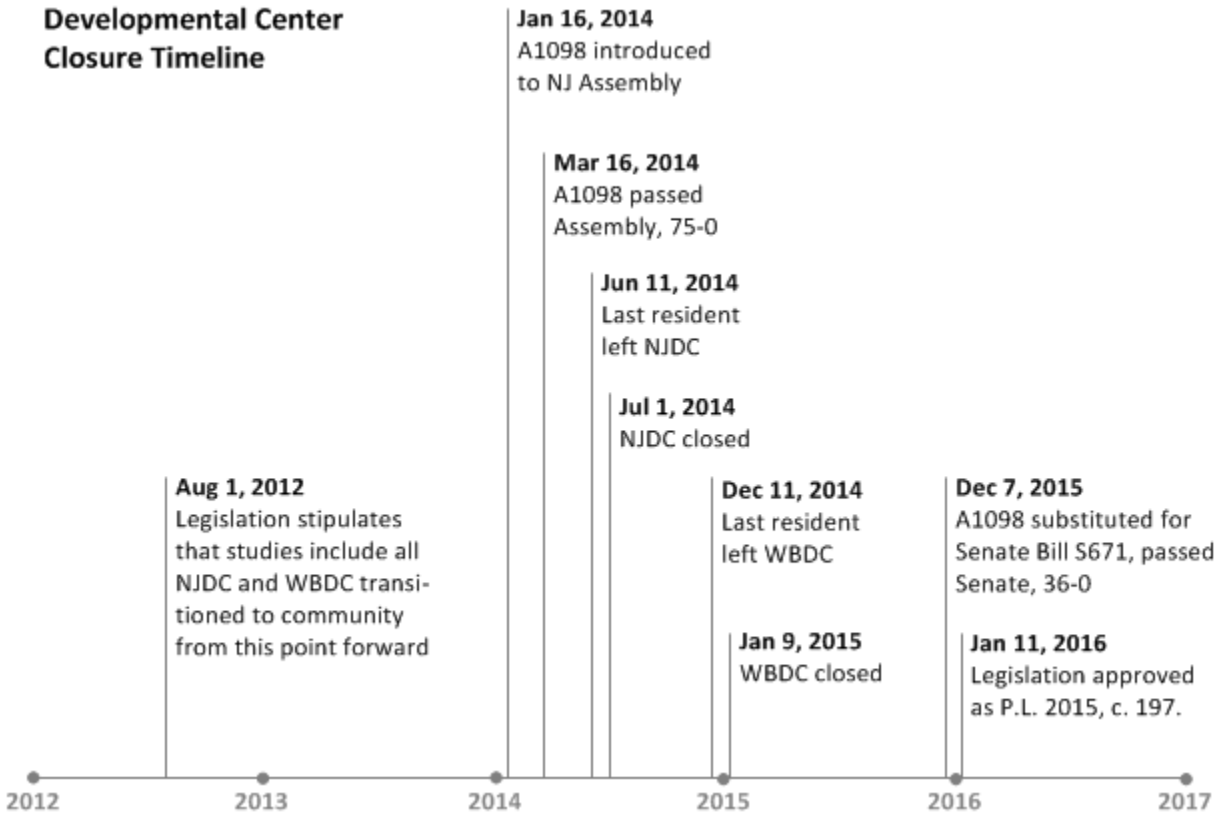

Figure 1: Timeline of DC closures

North Jersey Developmental Center

This report focuses on study findings for the 359 residents who were living at North Jersey Developmental Center (NJDC) on August 1, 2012. These individuals comprise the cohort slated for placement under the closure plan and identified for follow-up according to statute.

Placements began in August 2012 and concluded in June 2014 (see Figure 1). North Jersey Developmental Center officially closed on July 1, 2014. The findings in this report cover an initial multi-year study follow-up period from August 1, 2012, the legislatively-mandated starting

[8] Medicaid data were obtained from DMAHS.

point for the evaluation, until June 30, 2015, one year following NJDC's closure. Year two covers the time frame from July 1, 2015 through June 30, 2016. The information presented in this report will be updated annually for five years from the closure date as mandated.

Persons

North Jersey Developmental Center was situated in Totowa, Passaic County. In August 2012, its 359 residents were about equally likely to be male (51%) as female (49%) and were most likely to be under 65 years of age. The mean age of the population was 50.9 years.[9]

Table 1: Pre-placement characteristics of North Jersey residents on August 1, 2012 (N=359)

Characteristics	%
Gender	
Male	51.0%
Female	49.0%
Age Group	
22 - 44 years	29.0%
45 - 54 years	26.5%
55 - 64 years	28.1%
65+ years	11.7%

With information from DDD staff, guardians make placement decisions for their relatives. All placements, from initial post-closure placements to subsequent placements must be approved by the guardians of the individuals placed. Of the 157 former residents of North Jersey who were placed in other developmental centers, 98 or 62% had private guardians, primarily parents[11] and siblings, but also including aunts/uncles, cousins, other family members, and friends. About a quarter (42 or 27%) had state guardians, while 17 (11%) were their own guardian. Among the community placements, private guardians also were most common with 47% of the residents with community placements having family guardians, predominantly parents or siblings, while 38% had state guardians and 14.5% were their own guardian. Among the 42 individuals who were initially moved to another developmental center, but were subsequently moved into the community,

Table 2 Guardians by placement type (N=337)[10]

Guardian Type by Placement	N	%
Developmental Center	157	-
Private	98	62.4%
State Guardian	42	26.8%
Self	17	10.8%
Community	138	-
Private	65	47.1%
State Guardian	53	38.4%
Self	20	14.5%
DC to Community	42	-
Private	26	61.9%
State Guardian	12	28.6%
Self	4	9.5%

[9] The North Jersey Developmental Center also housed the Special Support Unit for "Court adjudicated minor male juveniles with developmental disabilities." At the time of closure, two individuals were placed in this unit.
[10] Chart does not include thirteen individuals who passed away, eight individuals that went to skilled nursing facilities and one that was discharged before placement.
[11] Including step, foster and spouses of biological parents, i.e., in-laws.

26 (62%) had private guardians, 12 (29%) had State guardians, and 4 (9.5%) were their own guardians.

Residential Settings

From August 2012 through June 2014, 200 individuals or 56% of the 359 North Jersey Developmental Center residents were transferred to other developmental centers.[12] Of the remaining 159 residents, 137 moved to the community. Thirteen residents died prior to the closure. One person was discharged and eight people were moved to skilled nursing facilities.

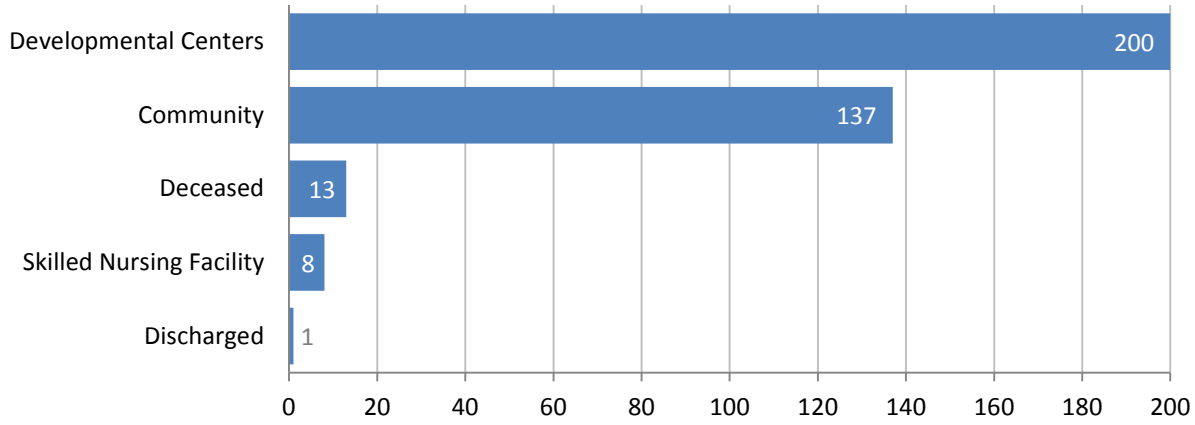

Figure 2: Placements from North Jersey after August 1, 2012 by type

Within eleven months following community placement, one of the North Jersey residents was admitted to a state psychiatric hospital for 21 days. Following discharge, this individual returned to the community. No former North Jersey residents placed in the community were admitted to state psychiatric hospitals thereafter.[13]

Table 3: Transfers to other developmental centers

Developmental Center	N	%
New Lisbon	68	34.0%
Vineland	64	32.0%
Woodbine	38	19.0%
Green Brook	21	10.5%
Hunterdon	9	4.5%
Total	200	100.0%

Of the 200 individuals from North Jersey who were placed in other developmental centers, 66% went either to Vineland or to New Lisbon (64 and 68, respectively). There were 38 (19%) who went to Woodbine, 21 (10.5%) to Green Brook and 9 (4.5%) were transferred to Hunterdon.

[12] Guardians approve placement decisions and may request placement in another developmental center if they feel it will be more appropriate.

[13] Former DC residents were cross-referenced with the DMHAS state psychiatric hospital database.

Moves to Different Settings

A move or transfer consisted of a change that followed the original residential placement, e.g., from a developmental center into the community or from the community into a developmental center. Moves also occurred when residents were transferred from one community residential placement agency to another or from one developmental center to another. Additionally, moves occurred from either a developmental center or a community residential placement into a Skilled Nursing Facility (SNF) as a permanent placement, related either to terminal illness or a chronic medical condition requiring nursing care.

For the purposes of this study, there were a number of changes that were *not* counted as residential "moves," including:

- Changes among cottages at the same developmental center.[14]
- Movement to another community residence operated by the same agency.
- Hospitalizations regardless of duration (as these are not residential placements).
- Rehabilitation in a short-term, temporary skilled nursing or rehabilitation facility following hospitalization (with the goal of returning to a residential placement).[15]

Based on this definition and analysis, 64, or 17.8%, of the 359 residents from NJDC experienced residential movements following their initial placement. For all 64 residents who moved, only one such move occurred.

[14] A common example was a resident with an initial placement on the grounds of a developmental center who then moved either among cottages or back and forth between a cottage and the DC infirmary.

[15] In some instances, e.g., when the resident had a terminal illness, placement in a Skilled Nursing Facility was a residential placement. Where there were questions regarding an SNF placement, DDD staff looked for and examined the Pre-Admission Screening and Resident Review (PASRR) document for guidance.

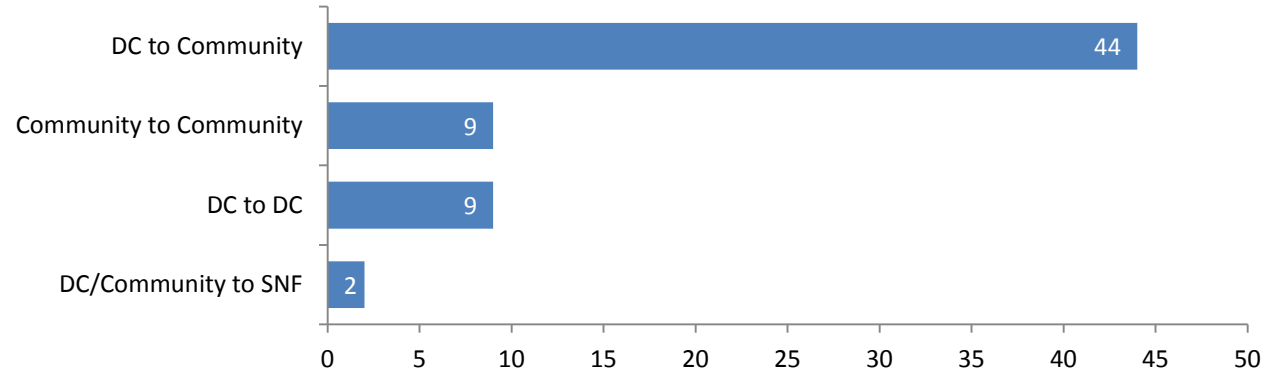

Figure 3: Types of placement moves (N=64)

As seen in Figure 3, the majority of moves were from a developmental center to the community: 44 of the 64 moves, or 68.8%, were of this type.[16] Movement among community placement agencies occurred in 9 instances or 14.1% of all moves. Nine residents experienced movement from one developmental center to another, 14.1% of all moves. Finally, two moves, or 3.1%, entailed placement in a SNF from a developmental center or a community placement setting.

Community Services

Services for people affected by the closure of North Jersey Developmental Center are driven by a customized, person-centered service plan, regardless of the placement setting. Hence, individuals receive a service (e.g., nursing) if it is incorporated into their individual service plan and conversely, will not receive the service, in either the developmental center or the community, if it has not been identified as a need in their plan. The most recent Community Care Waiver renewal application was approved in March 2017 and added several new services and rehabilitative therapies as available options.[17]

The amount of staffing in community placements varied depending on the number and needs of individuals. To examine the staffing at these community placements, a random sample of 14

[16] There were a substantial number of such placements because at the time of the closure, some individuals moved to Southern region developmental centers as these were the only developmental center placements available. These placements occurred with the understanding that when community slots further north became available that these individuals would be moved.

[17] The renewal application was approved March 31, 2017 with the addition of the following new services and rehabilitative therapies that were previously unavailable: behavioral supports, career planning, prevocational training, supported employment-small group employment support, and habilitative therapies (occupational/physical/speech, language and hearing).

community placements was selected.[18] There was an average of 82 weekly direct staffing hours per capita in these placements, ranging from 50 to 196 hours per person per week.

The number of direct care staffing hours was not significantly associated with the number of residents in the placement.[19] However, other factors may come into play in determining staffing levels. Four of the facilities were managed by the same organization and thus offer the best basis for comparison. In three instances, both the weekly per capita hours and hours across shifts were similar: in these cases, the residents all attended day programs so there were no direct service providers on shift during the day on weekdays. However, in one facility, a direct service provider was scheduled to work during the day on weekdays to provide services for a resident who preferred to not leave during the day for a weekday program or activity. Thus, for this facility, there was a staff person present essentially 1:1 to deliver in-house day programming for the individual who remained there during the day. Behavioral needs varied across these four programs with behaviorists retained for two hours a week in two of the homes and five hours a week in the other two homes. Most programs planned for minimal staff during weekday day-time hours from about 7 am to 3 pm when individuals were expected to be attending day activities elsewhere. Conversely, programs kept higher staffing levels on weekends when individuals were present all day and might leave the residence for shopping, lunch or social or recreational activities. In the event that an individual is sick and unable to attend a day program, staffing is provided. All programs allow for the possibility of hiring per diem staff when circumstances warrant.

Of the 137 individuals in community placements, all but three participated in some type of formal day activity, most often a day habilitation program. Day habilitation programs provide training and support for individuals with developmental disabilities to participate in activities based upon their preferences and needs, as specified in their service plans. Services are structured to allow for maximum self-direction and choice. Activities include, but are not limited to, vocational activities, life skills, personal development and community participation.

One hundred and twenty-nine of the 134 individuals who participated in a day program were engaged in a DDD-funded formal adult training program available outside of the residential placement setting. These programs varied, depending on the level of support needed. An additional five individuals participated in State Plan Medicaid-funded medical day programs

[18] Every 10th individual was selected and the program descriptions for their community facilities reviewed.
[19] Pearson correlation = .294, not statistically significant at the .05 level.

offering "medical, nursing, social, personal care and rehabilitative services" along with lunch and transportation to and from the program.[20]

Of the three individuals who did not participate in a formal day program, one person received informal in-home supports; this individual was retired and chose a less formal set of activities related to personal preferences. Another individual was not engaged in day activities at the time due to hospitalization. Another individual was engaged in competitive employment.

Table 4: Types of day programs

Day Program Types	N	%
DDD-Funded Adult Training (various types)	129	94.2%
State Plan Funded Medical Day Programs	5	3.9%
DDD-Funded In-Home Supports	1	0.7%
Competitive Employment	1	0.7%
Hospital	1	0.7%
Total	137	100.0%

The Community Care Waiver provides transportation between the individual's residence and the location of their day habilitation services as a component part of habilitation service.[21] Adult Medical Day program transportation is funded through State Plan Medicaid. In addition, some medical transport for doctors' appointments, hospitals and therapies can be paid for by the Medicaid State Plan. If the resident attends an adult medical day program, transportation must be provided by the day program.

Medical and dental care is governed by the licensing standards for residents of group homes as set forth in New Jersey's Administrative Code. For medical care, the relevant portion of section 10:44 mandates that "Each individual shall have an annual medical examination."[22] The Administrative Code further requires that documentation of visits be maintained in the consumer's record.

[20] See http://www.nj.gov/njhealthlink/programdetails/adult_medical_day_services.html?pageID=Adult+Medical+Day+Care+Services&file=file:/njhealthlink/programdetails/adult_medical_day_services.html&whichView=popUp

[21] See http://www.nj.gov/humanservices/ddd/documents/Documents%20for%20Web/CCWRenewalCMSApproved10_1_08.pdf

[22] N.J.A.C. 10:44B (2014). Manual of Standards for Community Care Residences.

Information regarding routine medical care was obtained from the DDD's Client Information System (CIS). Analysis showed that 127 individuals or about 93% had at least one medical examination following their placement.

As shown in Figure 4, following placement, 29 individuals had one medical examination, 65 had two examinations, 31 had three examinations and two individuals had four examinations. Seventy-six individuals had documented annual medical examinations.

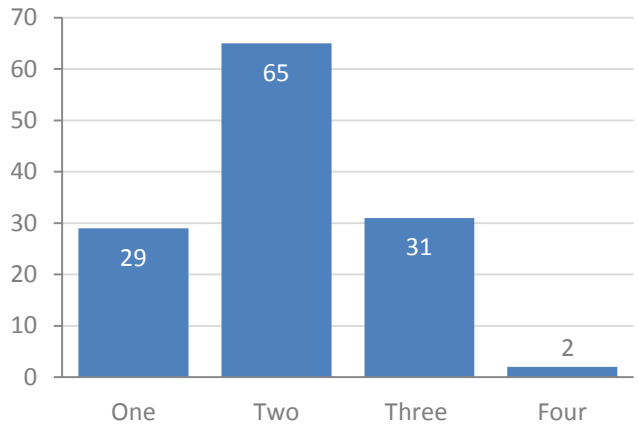

Figure 4: Number of medical examinations per individual, among those who had medical exams (n=127)

The licensing standards for residents of group homes and community care residences as set forth in New Jersey's Administrative Code[23] mandate "Each individual shall, at a minimum, have an annual dental or oral examination." Information regarding dental care was obtained from the Department of Human Services' Medicaid Management Information System (MMIS). Procedure codes associated with dental claims for oral examinations and treatment were identified by the DMAHS's Dental Director and used in the analysis.

One hundred and nineteen individuals (86.9%) had some type of oral examination, prophylaxis or debridement from the time of their placement through June 30, 2016.[24] Seventy-five of these individuals received dental examinations on an annual basis, with 63 receiving more frequent examinations every three to six months. Barriers to complete annual examinations appear to be behaviors that necessitated sedation, since sedation required medical clearances that either took additional time or could not always be obtained.

[23] See http://www.state.nj.us/humanservices/ool/documents/10_44A_eff_4_18_05.pdf

[24] Twenty-three residents did not receive one of these services through June 30, 2016. Of those 23, eight residents were deceased. One resident was placed in a skilled nursing facility and one resident is under the care of the Department of Children and Families and not receiving DDD services. Four residents were noted as being unresponsive or uncooperative with the dental exam. For four people, there was a dental procedure done but the mentioned services were not billed. One individual is in need of general anesthesia to complete an annual dental exam and completed the exam just outside of the report period. Three residents had issues getting the proper paperwork filled out by guardians. One individual is on the waiting list to receive services with UMDNJ after several visits with other dentists.

In addition to routine care, community residents also have access to emergency and hospital treatment. Danielle's Law mandates that direct support professionals in residential placement settings contact 9-1-1 when they believe a resident may be experiencing a life-threatening emergency.[25] In these situations, Emergency Medical Technicians (EMTs) and police typically respond, but the individual may or may not be transported to an emergency room, because not all Danielle's Law coded-incidents involve life-threatening emergencies. Staff members often act out of an abundance of caution and contact 9-1-1, regardless of the particulars, because they face a $5,000 fine when a "covered" incident is not reported and may not feel equipped to judge the severity of the event. Thus, even minor cuts or scrapes may generate 9-1-1 calls.

Table 5: ER visits post-placement

Number of ER visits	N	%
0	17	12.4%
1	19	13.9%
2	12	8.8%
3	19	13.9%
4	11	8.0%
5-6	21	15.3%
8-10	20	14.6%
11-14	10	7.3%
15+	8	5.8%
Total	137	100%

In the initial post-placement period (through 6/30/15)[26], 88 residents, or 64.2% of the 137 placed, had one or more incidents that triggered a 9-1-1 call in compliance with Danielle's Law. There were a total of 240 Danielle's Law incidents among these 88 residents, of which about three-quarters (77.5%) were medically driven and 22.5% were behaviorally driven. In year two, 77 residents (56.2% of the 137 placed), had one or more Danielle's Law incidents. Of the 243 incidents among these 77 residents, 78.2% were medically driven and 21.8% were behaviorally driven.

Table 6: Top 5 reasons for ER visits

Reason for ER visit	N
Gastronomy malfunction	13
Epilepsy	11
Contusion	8
Abrasion of other part of head	7
Vomiting	5

Claims data extracted from the State's Medicaid Management Information System (MMIS) were analyzed to determine whether residents placed in community settings utilized emergency rooms.[27] Of the 137 individuals in community placements, 120, or 87.6%, had

[25] See http://www.nj.gov/health/fhs/epilepsy/documents/danielles_Law.pdf

[26] Note: The initial study period is significantly longer than Year 2 (Initial Study Period: 7/1/13-6/30/15 and Year 2: 7/1/15-6/30/16)

[27] Only emergency visits occurring after community placement were considered. Emergency room visits were based upon the resident having an outpatient hospitalization with a review code for a type of emergency room visit. In order to avoid duplicate records for the same visit, the analysis also selected residents with procedure

emergency room visits during the initial post-placement period or in year two. The number of visits ranged from one to more than 15, with a median of four.[28] As shown in Table 6, the most common reason given for the emergency room visit was having a gastronomy malfunction.

Of the 137 North Jersey residents who moved to the community, 61 or 44.5% had one or more hospitalizations for medical conditions in either the initial post-placement period or year two, with gastrointestinal issues the most common reason cited (See Table 7).

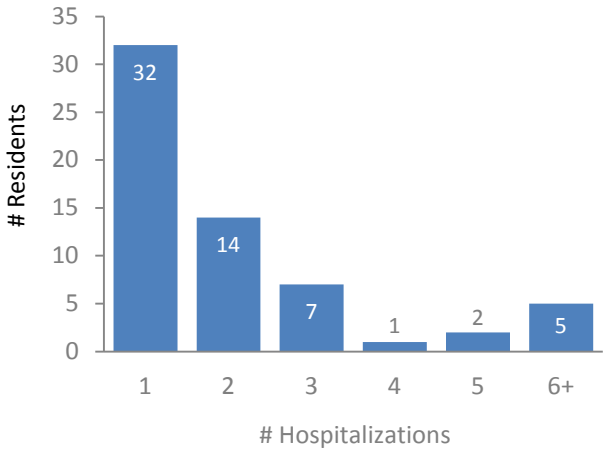

Figure 5: Number of hospitalizations per resident following placement, among residents who were hospitalized (n=61)

Table 7: Top 5 reasons for hospitalization

Reason for hospitalizations	N
Gastrointestinal disorders	16
Seizures	15
Psychoses	14
Respiratory illnesses	10
Kidneys	7

codes specifically associated with the emergency room visit rather than other billing codes occurring on the same date. These duplicate records were for the following types of procedures: catheter insertion, arm or leg splits, IV, injections or immunizations, feeding tubes, wound repair, overnight monitoring and diagnosis.

[28] Note that the median rather than the average is used because of the substantial spread and the presence of an extreme outlier (N=73 visits) which skews the average. The median means that half of the residents had more than 4 visits and half had fewer than 4 visits. It is important to note that Danielle's Law elevates ER visits as a consequence of mandated 9-1-1 calls.

Outcomes

This study examined a variety of outcomes for the individuals placed in the community. Comparisons were made to individuals transferred to other developmental centers, where feasible. Among the questions examined were the following:

- How were individuals functioning post-placement?
- Were they content with where they were living?
- Did they have contact with family and peers?
- How did their guardians perceive their quality of life?
- What types of health and behavioral health outcomes did they have?
- Did they have law enforcement involvement?

The tool used to assess individuals' functioning was developed by the Developmental Disabilities Planning Institute (DDPI), created in the mid-1990's as a university-based research organization and currently situated within Rutgers University. The New Jersey Comprehensive Assessment Tool (NJ CAT) is used annually to assess the placement cohort regardless of their residential setting.[29]

Assessments include composite scale scores for cognition and self-care and a single item that captured mobility. There are also summary levels completed regarding the resident's need for behavioral and medical supports. The assessments are completed by staff members who know the individual best.

The information reported here is the baseline score post-placement and compares scores for individuals placed in the community and in other DCs. Data were available for 121 of the 137 community residents. Of the 16 individuals for whom NJ CATs were not conducted, 11 had passed away post-placement, three were no longer in the care of DDD, and two were under the care of the Department of Children and Families. Data were available for 179 of the 209 DC placements. Of the 30 individuals for whom NJ CATs were not conducted, eight had moved to SNFs, three were no longer in DDD care, 17 passed away, and two were unable to be contacted to set up the assessment. These scores will be compared to subsequent annual assessments to determine changes in functioning for both populations over the five-year period.

Analyses examined several domains: cognition, basic self-care and mobility. To summarize the results, in the case of cognition and mobility, differences between the consumers placed in the

[29] Originally known as the Client Assessment Form (CAF) and later as the Developmental Disabilities Resource Tool (DDRT). Lerman, P., Apgar, D.H. and Jordan, T. (2009). The New Jersey Developmental Disabilities Resource Tool DDRT: History, Methodology and Applications. Developmental Disabilities Planning Institute, New Jersey Institute of Technology.

DCs and community were not statistically significant. Differences were statistically significant in the case of basic self-care.

The cognition scale consisted of 20 items.[30] Responses for each item were either "yes" or "no." Summed scores could range from "0" for individuals who were unable to complete any of the tasks to a maximum of 20 if individuals could perform all tasks. Items pertained to memory, telling time, recognition of size and shape, use of numbers, ability to write, and ability to read and understand meaning. Average scale scores for the community residents was 5.5 and for the DC residents was 5.4. A statistical analysis shows that between group differences were not statistically significant.[31]

The basic self-care need scale, a subset of the larger 21-item self-care need scale[32], consisted of 14 items. Scores for each item ranged from 0 to 3, with 0 indicating the individual has not done the activity, 1 indicating that the individual requires lots of assistance to perform the activity, 2 indicating that the individual can perform the activity with supervision, and 3 indicating the individual can perform the activity independently. Items pertained to feeding, drinking, chewing/swallowing, toileting, dressing, moving around, washing hands/face, brushing hair, adjusting water temperature, drying body after bathing, tying shoes (using laces or Velcro), and using tissues to wipe/blow nose. Total scores could range from 0 if individuals were unable to perform any of the tasks to 42 among individuals able to perform all tasks independently. The mean score for individuals living in the community was 23.8 (standard deviation=10.6) while the mean score for individuals living in a developmental center was 21.1 (standard deviation=14.6). Differences between the two groups were not statistically significant.

A single question captured mobility: *"Does (name) walk independently without difficulty, without using a corrective device, and/or without receiving assistance."* Analysis shows 59.5% of the community residents and 50.3% of the DC residents were able to walk independently. Again, the between-group difference was not statistically significant.

Are community residents satisfied with their residential placements – or would they prefer to live in a developmental center? Interviews were conducted with consumers to examine their perceptions of current and previous living situations. Many residents had significant cognitive impairment and could not be interviewed.[33] However, fifteen residents were able to be

[30] There were originally 21 items. One of the items was omitted due to missing values for more than 71% of the North Jersey residents.

[31] Note that all tests of statistical significance are t-tests of difference of means for independent samples where equal variances are not assumed.

[32] The longer scale includes household items that are not appropriate for this population.

[33] The researchers utilized information from the most recent NJ CAT (Comprehensive Assessment Tool) to determine the likelihood that former residents could make a comparison and were able to recollect past

interviewed about their housing preferences.[34] Fourteen of the fifteen residents interviewed expressed a preference for living in the community; none of these residents wanted to return to North Jersey. There was one resident who was unhappy in his current group home and expressed that he would either like to move to another group home or back to North Jersey.

Of the fourteen residents who did not want to return to North Jersey, their preferences for the type of community setting in which they would like to live varied. Five consumers were happy with their current placement and did not want to move. When asked where he wanted to live, one of these consumers responded "in the group home." When probed with the question if there was anywhere else he would like to live, he said "no." Four individuals wanted to move to other group homes, largely because of conflicts with their housemates or a desire to live with a famiy member. One individual who had a problem with his housemate said "I do not like that house. [My housemate] really bothers me… I get a paycheck. [My housemate] is really jealous." Two residents wanted to live with their families. One consumer who preferred her group home but wanted to live with family said "My group home is better than North Jersey, but I want to live with my grandmother." Two consumers wanted to move to supervised apartments where they could have more freedom. One stated that a group home is where "you live by yourself, but there is staff there if you need them." This individual had previously lived in a supervised apartment and said that "I felt like I had more freedom." Lastly, one consumer said that he would like to move to a hotel and work, as he had previously.

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experiences. Three items were utilized for this purpose: whether former residents knew the difference between shapes, whether they were able to remember events that happened a month or more ago, and whether the residents were able to understand a joke or story. Additionally, consumers who were their own guardians were included in the survey sample.

[34] Nineteen were determined eligible to be interviewed based on the NJ CAT information. Four of the nineteen were unable to participate. Of these four individuals, two were their own guardians were unable to respond to the interview and are awaiting BGS guardianship. Results are based upon in-depth interviews with fifteen community residents. The same DHS staff person interviewed each of these residents, either at the consumer's residence or day program. The residents were asked what they liked and disliked about their lives at North Jersey and where they were living now, and where they would prefer to live if given the choice.

Information about contacts residents have with family was obtained from data collected by case managers during quarterly or monthly Alternative Living Arrangement (ALA) meetings. In the initial post-placement period, 11 of the 133 individuals in the community for whom data were available, had no family.[35] Of the remaining 122 with family, 78 had at least annual contact. Of the 78 who had contact with family, data regarding the frequency of contact were available for 71. Of these 71, there were 33 who had weekly contact, 17 who had monthly contact, and 21 who had at least annual contact. By Year 2, two individuals had passed away and 12 were missing data.[36] Thus, family contact was reported for 121 people. Of these 121, eight had no family. Of the remaining 113, 78 had contact with their family. Of the 78 who had contact with family, data about the frequency of contact were available for 72. Of these 72, 34 had weekly contact, 15 had monthly contact, and 23 had at least annual contact. [37]

Table 8: Family involvement among community residents

Family involvement	N	%
Initial Post-Placement Period		
Family contact	78	63.9%
No family contact	44	36.1%
Year 2		
Family contact	78	63.9%
No family contact	35	36.1%

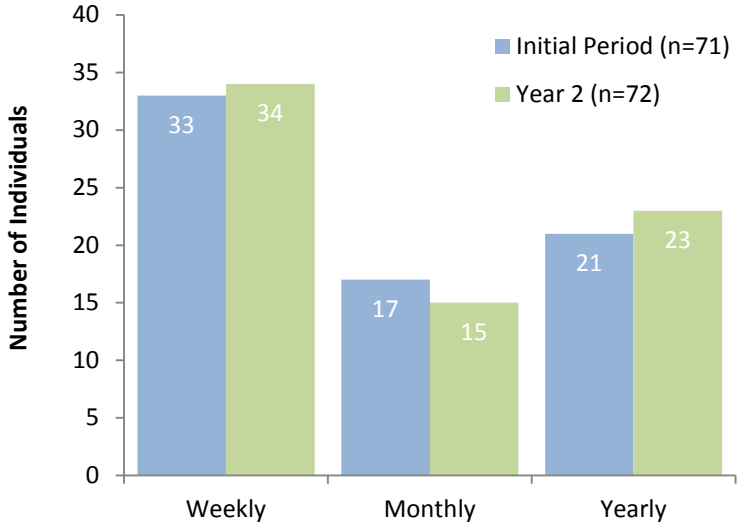

Figure 6: Frequency of family contact

In both the initial placement period and in year two, the majority of community residents had access to peers, primarily on a daily basis: 96.2% in the initial post-placement period and 97.5% in year two.

[35] In the initial study period, 4 individuals were missing ALA forms. Efforts were made to obtain these forms from case managers.

[36] Missing data was due to ALA forms not being accessible or completed. Efforts were made to obtain these forms from case managers.

[37] Findings from the survey were reinforced by analysis of records from the Alternate Living Arrangement (ALA) form. The form documents family contact by either the month or quarter. In the initial study period, the ALA data were available for 133 of the 137 residents placed in the community. In year 2, the data were available for 123 of the 137 residents placed in the community.

The study also incorporated the perspectives of private guardians about the North Jersey cohort's quality of life. A survey[38] was mailed to the family/guardians of 88 of the 89[39] individuals who had been placed in the community and who had private guardians (i.e., family members, friends, or advocates).[40] Family/guardians who did not respond to the initial mailing received a postcard reminder followed by up to three phone calls.

As of August 14, 2017 family/guardians of 63 former North Jersey residents had responded to the survey, a response rate of 71.6%.[41] Sixty respondents (95.2%) were related to the former North Jersey resident, while three were friends or family friends (4.8%). Relatives were primarily either siblings (55.6%) or parents (33.3%). Other family members included an aunt or uncle, grandparent, a niece or nephew and a cousin (6.3% combined).

Nearly all (88.9%) of the respondents (N=56) had visited former North Jersey residents in their community placements. Only one respondent had no contact, direct or indirect, with the individual placed. Of the seven respondents who did not visit, three contacted staff at the residence. One respondent had contact with residents by phone or email and two respondents had contact with staff and contact with the residents by phone or email. The contact totals summed to more than 63 because respondents could have multiple methods of contact. For example, nineteen individuals both visited and had contact via phone or email. Of the twenty-nine that contacted staff, twenty-four also visited the residence.

Respondents were asked about perceptions of their relative's quality of life. Respondents could answer indicating their degree of happiness or satisfaction with aspects of the residents' life and care. Numbers were assigned to the ratings such that higher scores indicated a more positive rating, while lower scores represented a more negative rating. They also were asked to provide a summary rating regarding how their relative is doing overall in their current living situation.

Ratings focused on family and private guardian perceptions of the residents' living situation and community programming. Respondents were asked to indicate their happiness with each of thirteen aspects of the community resident's current situation. Ratings were assigned scores as follows: "very happy"= 5; "somewhat happy" = 4; "neither happy nor unhappy" = 3; "somewhat unhappy" = 2; and "very unhappy" = 1.

[38] See Appendix. Items were based upon surveys conducted of previous institutional closures in New Jersey.
[39] Contact information was not available for one individual with a private guardian until after the period during which the survey was being administered.
[40] Of these 88 individuals, 63 were initially placed in the community and 25 moved first to another DC and then to the community.
[41] Of the twenty-five that have yet to respond, six were contacted by phone and per their request were sent a new survey either by mail or email, but did not complete the survey during the subsequent month. Family/guardians of five individuals stated they did not wish to complete the survey and fourteen could not be reached.

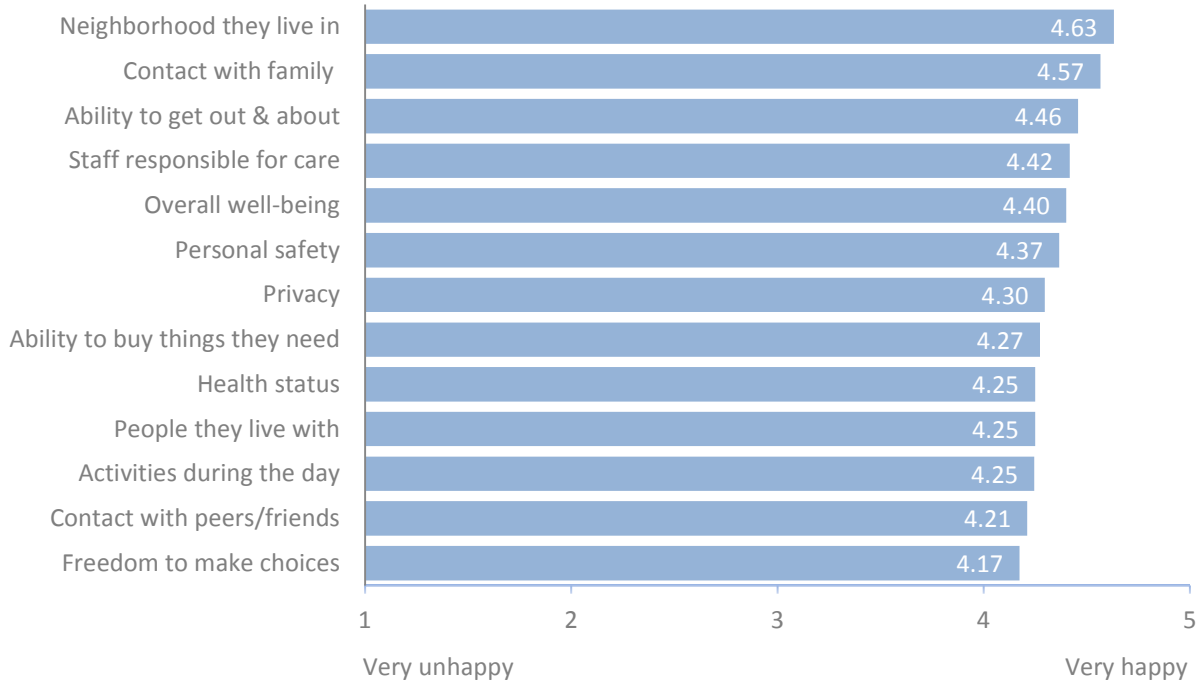

Figure 7: Average rating of family guardians' happiness with consumers' current living situations.

The average scores for each of the 13 items produced a 4 or higher with most items falling between 4.0 and 5.0 (indicative of being between "somewhat happy" and "very happy").[42] The rating for the neighborhood they live in at 4.63 was the highest for any of the community ratings.

Respondents also were asked to indicate their satisfaction with each of seven aspects of the community resident's program, including availability of medical, dental, and behavioral health services, transportation to appointments, day and leisure activities, and the daily routine. Ratings were assigned scores as follows: "very satisfied"= 5; "somewhat satisfied" = 4; "neither satisfied nor dissatisfied" = 3; "somewhat dissatisfied" = 2; and "very dissatisfied" = 1.

Reported satisfaction was evident in the item averages, which ranged from a low of 4.23 to a high of 4.74, where a "5" indicates the respondent is "very satisfied." The rating for transportation to appointments or programs at 4.74 was the highest for any of the community programming ratings

[42] The legislation specifically mentions personal safety and health status, both of which are rated over 4.

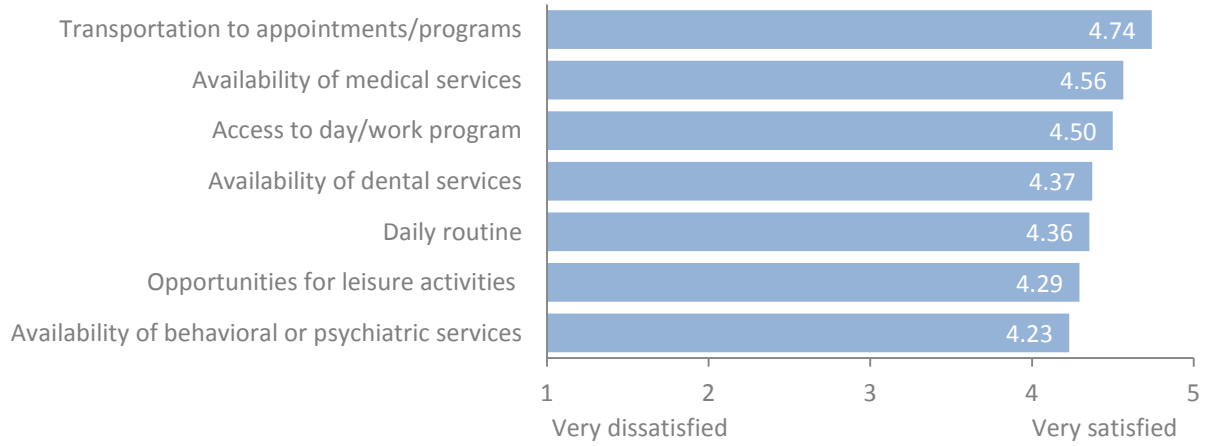

Figure 8: Average ratings of programming and services

A comparison was made to how private guardians for the North Jersey residents transferred to other developmental centers perceived quality of life in these DCs. Surveys were sent to 155 family/guardians of DC residents with contact information.[43] As of August 14, 2017 surveys had been received from 57 family/guardians. These included six residents with two family respondents each; one survey each was chosen at random, leaving 51 surveys and a response rate of 63.8%. Most of the respondents were family members, primarily siblings (49.0%) or parents (35.3%). Other family members included an aunt or uncle, grandparent, a niece or nephew and a cousin (15.7% combined).

Table 9: Guardian perception of relatives' well-being Note: 15.7% equates to 8 people and 3.2% equates to 2 people.

How relative is doing overall?	Community (N=63)	DC (N=51)
Excellent/Good	79.4%	84.3%
Fair/Poor	17.5%	15.7%
Don't know/missing	3.2%	0.0%

Comparisons between perceptions of family/guardians of community and DC residents also were made with regard to their happiness with various aspects of quality of life and satisfaction with community programming. In response to how their relative is doing overall 79.4% of the community guardians and 84.3% of the developmental center guardians reported (in table 9) that s/he was excellent or good.[44] With one exception, none of the between-group differences was statistically significant. The exception was the "transportation to appointments or programs". Family/guardians of community residents were significantly more likely to feel very satisfied with transportation to appointments or programs if individuals were living in the community.

[43] Each person who did not respond to the initial mailing received a postcard reminder followed by at least three phone calls.
[44] No statistical significance at the .05 level.

The study also examined health status outcomes, such as the need for medical and behavioral health supports and mortality. The NJ CAT tool examines the baseline status post-placement for residents' need for assistance based on their medical and behavioral health. Descriptions of the scales can be found in the appendix.

The measure of the need for medical supports considers three levels of medical need for assistance.[45] As shown in Figure 9, both DC and community residents predominantly need specialized medical care, but compared to the community residents, a greater percentage of DC residents were reported to need on-site nursing care.

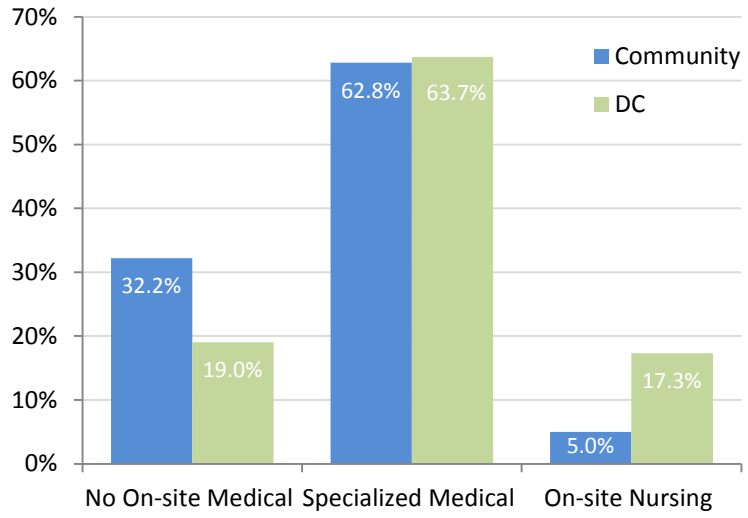

Figure 9: Medical assistance by residential placement type

The Behavioral Supports Level has scores ranging from 1 to 4, with higher scores associated with behaviors requiring more intensive support and environmental modifications.[46] A comparison of data for community and DC residents show that community residents most commonly needed formal behavioral health supports while approximately equal percentages of DC residents needed either formal supports or intensive supports. About a quarter of DC residents needed no on-site support. Decisions regarding

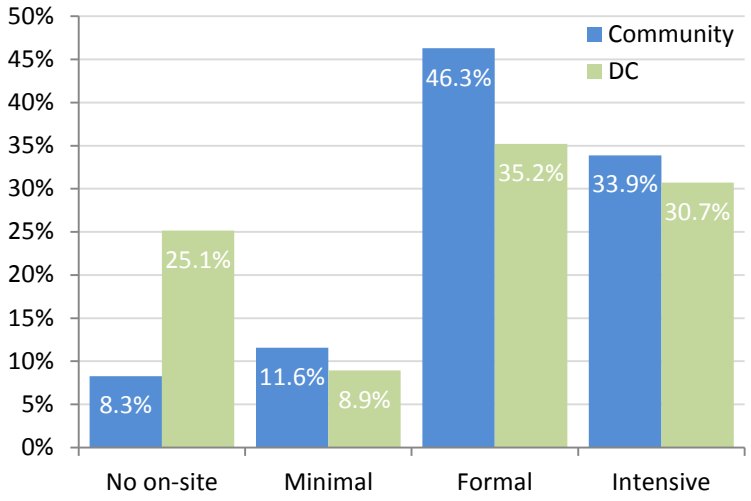

Figure 10: Need for behavioral supports by DC and community residents post-closure

[45] Analysis of these scales showed both high test-retest reliability using the same raters at two intervals and good inter-rater reliability. See Lerman, P., Apgar, D.H. and Jordan, T. (2009). The New Jersey Developmental Disabilities Resource Tool DDRT: History, Methodology and Applications. Developmental Disabilities Planning Institute, New Jersey Institute of Technology, 196-197.

[46] Lerman, et al., op. cit., 188-190.

residential placements were made by the residents' guardians. Among individuals who selected to live in the community, greater behavioral health supports were required than among people who moved to a developmental center.

Among the cohort of 359 North Jersey Developmental Center residents slated for placement, 36, or 10.3% passed away in the initial post-placement period (from 7/1/13 through 6/30/15) and 13, or 3.6% passed away in year two. Thirteen, or 3.6%, passed away in the developmental center prior to placement. Thirty-six residents, or 10.3%, passed away following placement: 16 after placement in developmental centers, 11 following placement in the community, 8 following placement in skilled nursing facilities, and 1 following placement in a hospice facility. There were an additional three residents who were discharged to family out-of-state whose outcomes were unknown.

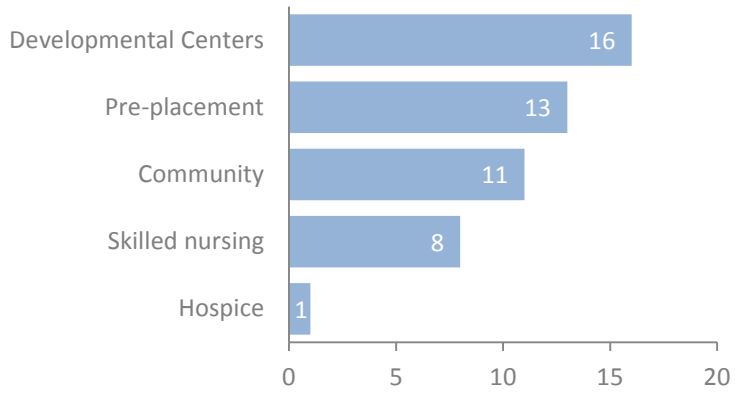

Figure 11: Number of deaths by placement type

The researchers used a cut-off of six months post-placement to look in detail at the cases in which the death occurred in close proximity to the move. There were a total of ten deaths that occurred within six months of placement. Nine had significant medical issues, such as cancer, seizures, or stroke; two of these nine were admitted to a skilled nursing facility. One death was caused by asphyxia secondary to choking on food.[47]

The researchers also examined unusual incidents that may have occurred using the Department of Human Services' Unusual Incident Reporting and Management System (UIRMS), which captures information on a range of unusual incidents including operational (e.g., a minor fire extinguished by staff), operational breakdowns (when an outage or disruption poses a threat to health and safety and/or impacts facility operations), unexpected staff shortages (if the shortage results in the inability to safely evacuate residents or if appropriate levels of supervision cannot be maintained), criminal activity, or media interest around a reportable incident. Regulations stipulate that criminal activity involving individuals served or staff "is reportable when the event constitutes a crime in accordance with NJ criminal statutes and police take a report or file charges." Entries in the UIRMS database include the incident code, date of the incident, the responding party, and the action taken. However, there can be a lack

[47] The death was investigated by the Office of Investigations and the staff member was terminated and placed on the registry of offenders.

of clarity and standardization in the documentation of law enforcement involvement. This is largely because the criminal justice system is not obligated to provide the Division with updates on its work. Therefore, incident codes were augmented by a review of the incident narrative which resulted in 41 incident reports through June 30, 2016, with 27 from placement through the end of the initial post-placement period (6/30/15) and 14 in year two. One staff member was indicted as a result of exploiting consumers. The incidents involved loss or theft of controlled substances, theft of money, and instances where residents destroyed property or acted out, with the police primarily performing peace-keeping functions.

To supplement the data in the UIRMS database, data also was gathered through case manager surveys. The data from these survey show that seven individuals living in the community were the victims of a crime that had been reported to the police while four were perpetrators. In nine of these 11 instances, the police took a report and in five, the police investigated or are continuing to investigate. In two instances, the consumers were victims of theft; in one instance, the consumer was a perpetrator of theft. In two instances, reports of neglect were filed.

Appendix A: Medical and Behavioral Supports Levels Table

NOTE: For Figure 9, the ambulation support groups were combined to focus on the level of medical care required. Thus, Levels 1 and 2, 3 and 4, and 5 and 6, as outlined below, were combined.

Medical Supports

Level 1: No On-Site Specialized Medical and No Ambulation Support Required Persons may have one or more medical conditions (i.e., high blood pressure, asthma, ulcers, etc.), but no special medical attention is needed on-site besides that normally provided by day and residential support staff such as, but not limited to, medication administration, scheduling of medical appointments, transportation to doctor's appointments, etc. Persons are able to walk independently with or without corrective devices and/or independently use wheelchairs – needing no assistance transferring or moving from place to place.	Level 2: No On-Site Specialized Medical, but Ambulation Support Required Persons may have one or more medical conditions (i.e., high blood pressure, asthma, ulcers, etc.), but no special medical attention is needed on-site besides that normally provided by day and residential support staff such as, but not limited to, medication administration, scheduling of medical appointments, transportation to doctor's appointments, etc. However, Persons can walk only with assistance from another person and/or use wheelchairs and need assistance from staff when transferring and/or moving from place to place.
Level 3: Specialized Medical Supports Required, but No Ambulation Support Required Persons have one or more medical conditions (i.e., respiratory, digestive, cardiovascular, etc.) and these conditions require special medical attention by on-site day and residential staff (non-nursing) who have received appropriate training. Treatments may include, but are not limited to, dressing or wound care; catheter or colostomy emptying and maintenance; monitoring of oxygen use; insulin administration; turning and positioning; use of Epi Pen for allergic reactions; and administration of enemas. Agency is responsible for providing and maintaining the appropriate medical training for staff. Training may be accessed through and/or provided by local Visiting Nurses' Associations (VNAs), agency nurses, hospitals, Persons' physicians, etc. Persons are able to walk independently with or without corrective devices and/or independently use wheelchairs – needing no assistance transferring or moving from place to place	Level 4: Specialized Medical and Ambulation Support Required Persons have one or more medical conditions (i.e., respiratory, digestive, cardiovascular, etc.) and these conditions require special medical attention by on-site day and residential staff (non-nursing) who have received appropriate training. Treatments may include, but are not limited to, dressing or wound care; catheter or colostomy emptying and maintenance; monitoring of oxygen use; insulin administration; turning and positioning; use of Epi Pen for allergic reactions; and administration of enemas. Agency is responsible for providing and maintaining the appropriate medical training for staff. Training may be accessed through and/or provided by local Visiting Nurses' Associations (VNAs), agency nurses, hospitals, Persons' physicians, etc. Persons can walk only with assistance from another person and/or use wheelchairs and need assistance from staff when transferring and/or moving from place to place.
Level 5: Specialized On-Site Nursing, but No Ambulation Support Required Persons have one or more medical conditions (i.e., respiratory, digestive, cardiovascular, etc.) and these conditions require on-site nursing care by a Registered Nurse (RN) or Licensed Practical Nurse (LPN). Treatments may include, but are not limited to: oral and/or nasal suctioning; Intravenous medications; tube feeding; and catheterization. Nurses may also be responsible for overseeing medication administration, and medical management of Person care with off-site medical providers. Agency is responsible for providing and maintaining the appropriate medical training for staff. Training may be accessed through and/or provided by local Visiting Nurses' Associations (VNAs), agency nurses, hospitals, Persons' physicians, etc. Persons are able to walk independently with or without corrective devices and/or independently use wheelchairs – needing no assistance transferring or moving from place to place.	Level 6: Specialized On-Site Nursing and Ambulation Support Required Persons have one or more medical conditions (i.e., respiratory, digestive, cardiovascular, etc.) and these conditions require on-site nursing care by a Registered Nurse (RN) or Licensed Practical Nurse (LPN). Treatments may include, but are not limited to: oral and/or nasal suctioning; Intravenous medications; tube feeding; and catheterization. Nurses may also be responsible for overseeing medication administration, and medical management of Person care with off-site medical providers. Agency is responsible for providing and maintaining the appropriate medical training for staff. Training may be accessed through and/or provided by local Visiting Nurses' Associations (VNAs), agency nurses, hospitals, Persons' physicians, etc. Persons can walk only with assistance from another person and/or use wheelchairs and need assistance from staff when transferring and/or moving from place to place.

Behavioral Supports

Level 1: No On-Site Specialized Behavioral Supports Required Persons do not currently exhibit any inappropriate/rule violating, property destruction, self-injurious, or aggressive behaviors.	Level 2: Minimal Behavioral Supports Required Persons may exhibit some inappropriate/rule violating behaviors, including, but not limited to self-stimulation (body rocking/hand flashing), noises or other inappropriate vocalizations, non-compliance, and/or being disruptive, but no special behavioral support or environmental modifications are required by day and residential support staff.
Level 3: Formal Behavioral Supports Required Persons have one or more inappropriate/rule violating, self-injurious, or aggressive behaviors and these conditions require special behavioral support and/or environmental modifications by on-site day and residential staff who have received appropriate training. Support may include redirection, providing additional supervision, personal controls, and implementation of a formal behavioral plan. Behaviors may include, but are not limited to, having tantrums/outbursts, smearing feces, hitting own body/face/head, hitting others, property destruction, and/or kicking others. Agency is responsible for determining type and intensity of behavioral supports needed according to regulations developed by DDD. Agency is also responsible for preparing formal behavioral plans and providing staff training as needed.	Level 4: Intensive Behavioral Supports Required Persons have one or more inappropriate/rule violating, self-injurious, or aggressive behaviors and these conditions require a very high level of behavioral support and environmental modifications by on-site day and residential staff who have received appropriate training. Support may include providing one-on-one supervision, personal controls, and implementation of a formal behavioral plan. Behaviors may include, but are not limited to, sexual predatory behaviors, running away, eating or mouthing inedible objects, scratching self/others, hitting self/others, biting self/others, head-butting others, choking others, and/or kicking others. Agency is responsible for determining type and intensity of behavioral supports needed according to regulations developed by DDD. Agency is also responsible for preparing formal behavioral plans and providing staff training as needed.

Self-Care Support Needs

DDD Individualized Resource Tool

Level 1 to 4

The Individual Resource tool is a scientific instrument designed to gauge in general "how much" service a person needs and how much DDD funding will be allocated. The resource tool is designed on a model that assumes that the less an individual's capacity for self care the more s/he will need the assistance of others. Services and/or resources can be differentially allocated to these levels to ensure equity in system.

Level I

Lowest Support Time Needed, Highest Self Care Score

Description: A majority of people can do all activities of daily living, but may need help with public transportation.

Level II

Low Support Time Needed, Medium Self Care Score

Description: A majority of people can eat, drink, toilet, care for clothing, make bed, clean room, use microwave, prepare foods, and wash dishes. Not able to shop, count change, or do laundry.

Level III

Medium Support Time Needed, Low Self Care Score

Description: A majority of people can eat, drink, toilet, and dress. Not able to care for own clothing, use money, or count change. Caregivers spend a lot of time supporting individuals.

Level IV

High Support Time Needed, Lowest Self Care Score

Description: Many people may not be able to do anything for themselves, but a majority can eat and drink. Unable to toilet or dress themselves. Caregivers spend most time providing support

Appendix B: Family Guardian Survey

1. INTRODUCTION

In January 2016, the Legislature passed a law that requires the New Jersey Department of Human Services (DHS) to report on the well-being of individuals who have moved from North Jersey Developmental Center (NJDC) to the community during the closure process. As part of its statutory requirement, DHS' Office of Research, Evaluation, and Special Projects is collecting information from family members and/or guardians about former residents' current quality of life in their new living arrangements.

You have been identified as a family member and/or guardian of an individual who moved from NJDC after August 1, 2012 and now resides in a community placement. If this is accurate, we request that you complete a short survey to provide important information about your experience.

Please return your completed survey by March 17, 2017 in the stamped, addressed envelope provided. If another member of your household receives a survey, they should complete and submit their own survey.

Be assured that your participation and answers are voluntary and will not affect the services that your loved one receives in any way. Your individual responses will be kept confidential and data will only be reported in the aggregate.

If you have any questions, please contact Patricia Guyton at (609) 292-6232.

Thank you for your participation!

2. SURVEY

1. The identifying information below is needed to help us match residents to family members. That way, we will know whether we have information for each resident or consumer who left North Jersey Developmental Center for a community placement.

Your Name (Print):

Consumer's Initials:

2. In addition to being a guardian, how are you related to the consumer affected by the closure of North Jersey Developmental Center? I am: (Select ONE)

- ○ Grandparent
- ○ Parent/Stepparent
- ○ Sibling
- ○ Aunt/Uncle
- ○ Other (please specify)
- ○ Niece/Nephew
- ○ Cousin
- ○ Friend/Family friend

3. Have you had contact with the consumer while he or she has been in a community residence? (Check all that apply)

- ☐ Yes, I visited him or her
- ☐ Yes, we communicated by phone or email
- ☐ There was indirect contact (e.g., calls to staff)
- ☐ No, there was no direct or indirect contact

4. Regarding the consumer's current situation, how happy are you with each of the following? Please provide ONE answer for each item.

	Very happy	Somewhat happy	Neither happy nor unhappy	Somewhat unhappy	Very unhappy	NA or Don't know
The people they live with	○	○	○	○	○	○
The staff responsible for their care	○	○	○	○	○	○
The activities they have during the day	○	○	○	○	○	○
Their ability to get out and get around	○	○	○	○	○	○
The neighborhood they live in	○	○	○	○	○	○
Their personal safety	○	○	○	○	○	○
The contact they have with you or other family members	○	○	○	○	○	○
The contact that they have with peers and friends	○	○	○	○	○	○
Their freedom to make choices	○	○	○	○	○	○
Their ability to buy things they need	○	○	○	○	○	○
Their privacy	○	○	○	○	○	○
Their health status	○	○	○	○	○	○
Their overall well-being	○	○	○	○	○	○

5. How worried are you about each of the following at the consumer's current residence? (Select ONE response for each question)

	Very worried	Somewhat worried	Neutral	Not particularly worried	Not at all worried
Level of supervision	○	○	○	○	○
Preparation of staff to handle behavioral or medical problems	○	○	○	○	○
Staff turnover	○	○	○	○	○
Risk of abuse or neglect	○	○	○	○	○

Other (please specify)

6. How satisfied are you with each of the following? (Select only ONE answer for each question)

	Very satisfied	Somewhat satisfied	Neither satisfied nor dissatisfied	Somewhat dissatisfied	Very dissatisfied	Unsure or Don't Know
Your relative's daily routine	○	○	○	○	○	○
Opportunities for leisure activities	○	○	○	○	○	○
Access to either a day program or work activity	○	○	○	○	○	○
Transportation to appointments or programs	○	○	○	○	○	○
Availability of medical services	○	○	○	○	○	○
Availability of behavioral or psychiatric services	○	○	○	○	○	○
Availability of dental services	○	○	○	○	○	○

7. Overall, how would you rate how your relative is doing in their current living situation? (Select ONE)

- ◯ Excellent
- ◯ Good
- ◯ Fair
- ◯ Poor
- ◯ Don't Know

8. Do you want us to contact you regarding your responses or for some other purpose?

- ◯ Yes
- ◯ No

If yes, how can we contact you? Please list a phone number or email we can use.

9. Do you have any additional comments?

- ◯ Yes
- ◯ No

If yes, please specify (use the back of the page if necessary):

THANK YOU FOR YOUR ASSISTANCE!

PLEASE RETURN YOUR SURVEY IN THE STAMPED, ADDRESSED ENVELOPE THAT HAS BEEN PROVIDED BY March 17, 2017.