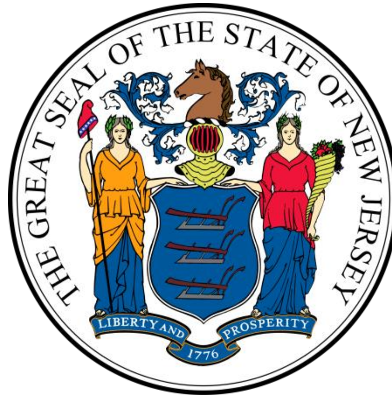
State of New Jersey
Department of Human Services

North Jersey Developmental Center Year Five Closure Report

NJ DHS Office of Research, Evaluation & Special Projects



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Introduction

In 2006, the 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] Thus, in 2007, DDD introduced its "Path to Progress" plan.[2] This plan aimed to enable residents of State Developmental Centers (DCs) who wanted to live in the community to do so. In 2011, a new statute created a five-person "Task Force on the Closure of State Developmental Centers" empowered to review all of the DCs and make binding closure recommendations. In July 2012, the members of 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. It is important to note that attrition and changes in the type of residential placement[6] complicate year-to-year comparisons.

This report presents data for the fifth year following the closure of North Jersey Developmental Center. It addresses the topics mandated in legislation focusing on persons, settings, services and outcomes. Unless specified, tables and graphs depict information for Year 5. Contextual comparisons as feasible and appropriate are made between consumers moved into community placements and those residing in developmental centers. Information was obtained from many sources and utilized varied methodologies including consumer and family surveys, specialized

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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 here: https://www.state.nj.us/humanservices/news/hottopics/Final_Task_Force_Report.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] Mortality and movements, primarily from DC's to the community and both DC and community to SNF reduce the population sizes as well as alter the characteristics of both community and DC cohorts.

data collection instruments, and multiple databases from the Division of Developmental Disabilities, the Division of Medical Assistance and Health Services, and the Division of Mental Health and Addiction Services.

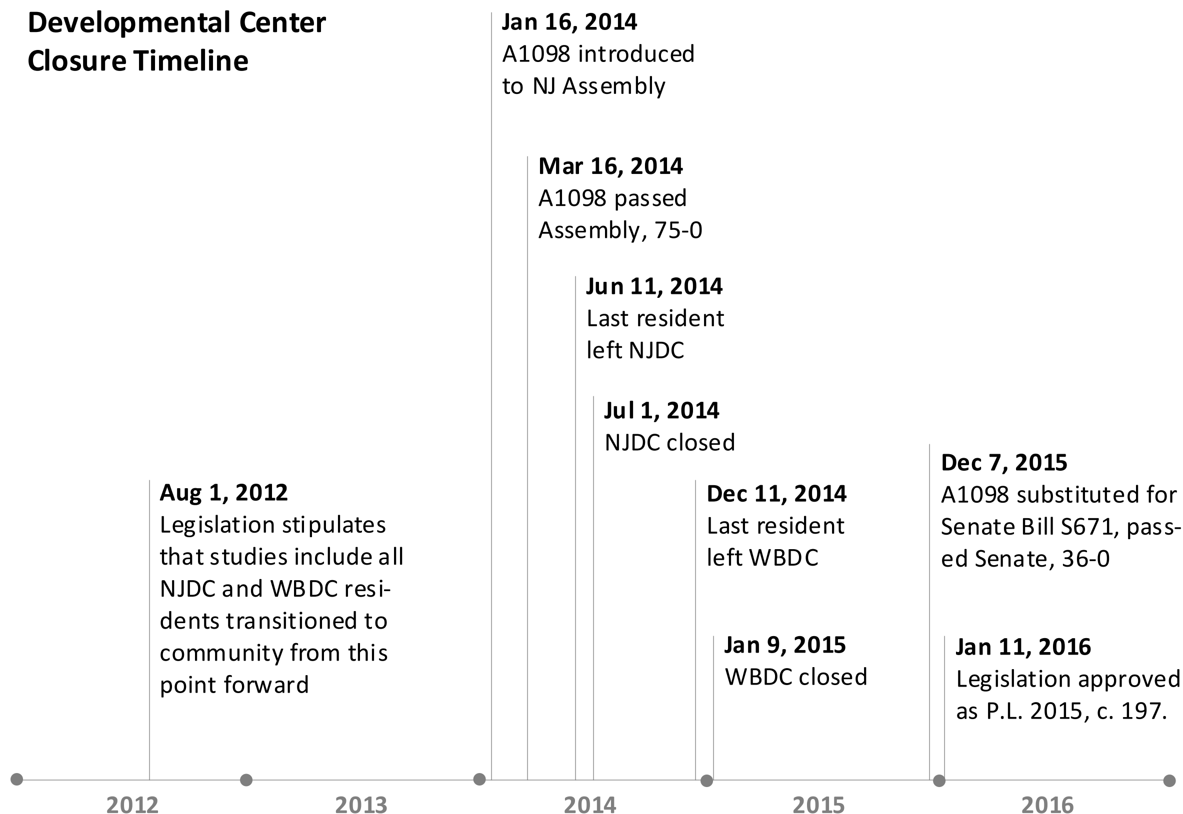

Figure 1 Timeline of DC closure

North Jersey Developmental Center

The evaluation focuses on the 359 residents who were living at North Jersey Developmental Center (NJDC) on August 1, 2012. They comprise the cohort slated for placement under the closure plan and identified for follow-up, according to statute. Placements began in August 2012 and culminated in June 2014 (see Figure 1). North Jersey Developmental Center officially closed on July 1, 2014. The findings for this fourth report[7] cover the period from July 1, 2018 until June 30, 2019. At the start of that time period, there were 291 members remaining in the cohort. Sixty-eight individuals are not part of this report. Thirteen individuals passed away prior to placement from North Jersey. Following placement, 36 passed away in developmental centers (n=16), community placements (n=11), hospice (n=1) and skilled nursing facilities (n=8). One person was discharged before NJDC closed and two individuals were discharged subsequent to leaving NJDC.

[7] Covering Year 5 post-closure.

There were six deaths and one discharge during the third year and nine deaths during the fourth year.

Table 1 Cohort attrition

Cohort Attrition	Year 1& 2	Year 3	Year 4	Year 5
Individuals at the start of the report period	359	307	300	291
Pre-placement deaths	13	--	--	--
Deaths	36	6	9	12
Discharges	3	1	--	1

Residential Settings

At the start of the report period, there were 291 former North Jersey Developmental Center residents. A total of 120 individuals or 41.2% of the 291 former North Jersey Developmental Center residents were residing in other developmental centers. Of the remaining 171 residents, 163 were living in the community. Eight residents were in Skilled Nursing Facilities (SNF). This report focuses on the 120 individuals residing in developmental centers and 163 persons living in the community.

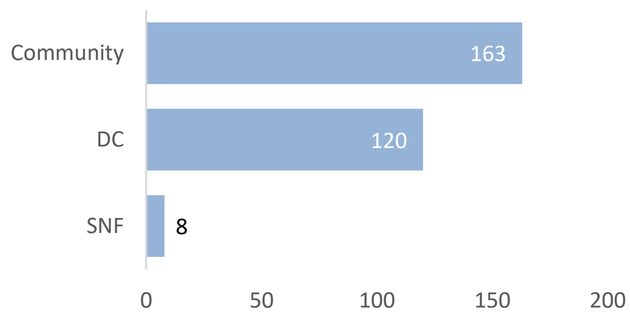

Figure 2 Placements from North Jersey by type as of 7/1/2018

Table 2 DC residents at start of report period by placement

Developmental Center	**N**	**%**
New Lisbon	38	31.7%
Vineland	32	26.7%
Green Brook	20	16.7%
Hunterdon	16	13.3%
Woodbine	14	11.7%
Total	120	100.0%

Of the 120 individuals from North Jersey who were living in Developmental Centers at the start of the report period, 58.3% resided in either New Lisbon or Vineland. An additional 16.7% resided in Green Brook, 13.3% were living in Hunterdon and 11.7% in Woodbine.

Persons

The 291 former NJDC residents who were cohort members in July 2018, were nearly evenly split by gender (50.2% were female) and tended to be 55 years of age or older. The mean age of the population was 55.3 years.

Table 3 Characteristics of North Jersey residents on July 1, 2018 (n=291)

Characteristics	Year 5
Gender	
Female	50.2%
Male	49.8%
Age Group	
23 - 44 years	21.3%
45 - 54 years	27.1%
55 - 64 years	29.2%
65+ years	22.3%

Placement decisions were approved by the residents' guardians. Of the 120 former residents of North Jersey who were living in other developmental centers at the start of the fifth year of the study, 76 or 63.3% had private guardians, primarily parents[8] and siblings. This group also included grandparents, aunts/uncles, cousins, and friends. Just over one-fourth (32 or 26.7%) of former residents had state guardians and twelve (10.0%) consumers served as their own guardian.

Among the 163 former North Jersey residents living in community settings at the start of Year 5, private guardians were also more common with 55.8% of the residents having private guardians, predominantly parents or siblings. A total of 30.7% of community residents had state guardians[9]; twenty-two consumers served as their own guardian.

Table 4 Guardians of DC and community residents by study year

Guardian Type by Placement	Year 1/2		Year 3		Year 4		Year 5	
	N	%	N	%	N	%	N	%
Developmental Center	156		137		128		120	
Private (Family)	97	62.2%	85	62.0%	81	63.3%	76	63.3%
State Guardian	43	27.6%	39	28.5%	35	27.3%	32	26.7%
Self/Pending	16	10.3%	10	7.3%	12	9.4%	12	10.0%
Community	181		167		167		163	
Private (Family)	92	50.8%	93	55.7%	94	56.3%	91	55.8%
State Guardian	64	35.4%	53	31.7%	52	31.1%	50	30.7%
Self	25	13.8%	21	12.6%	21	12.6%	22	13.5%

[8] Including step, foster and spouses of biological parents, i.e., in-laws.

[9] Of the three individuals in the community who passed away during Year 5, all had private guardians. Of the eight individuals in the DC who passed away, four had state guardians, three had private guardians and one was their own guardian.

There was one guardianship change during Year 5 for the DC residents. This individual was their own guardian at the start of Year 5 and was appointed a State guardian by the end of Year 5. There was two guardianship changes during Year 5 for the community residents[10]. One individual had a private guardian at the start of Year 5 and became their own guardian by the end of the year. The second individual had a State guardian at the start of the report period and was appointed a private guardian by the end of Year 5.

Moves to Different Settings

A move or transfer consisted of a change that followed the residential placement on the first day of the report period, occurring from July 1, 2018 through June 30, 2019. Changes included movement from a developmental center into a skilled nursing facility, a transfer from one community placement agency to another or a move from one developmental center to the community. Additionally, moves included a transfer from either a developmental center or a community residential placement into a 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.[11]
- 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 the individual to a residential placement).[12]

Based upon this definition and analysis, eight or 4.9% of the 163 individuals residing in community placements at the start of the report period experienced residential movements in Year 5. All eight individuals only moved once. Seven of the eight individuals moved from one community placement operated by one agency to another community placement operated by a different agency. One individual was residing in a community placement and was discharged from DDD services to move out of state with family.

[10] Guardianship changes for two individuals are not available. These two individuals were initially discharged to the care of DCF.

[11] 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.

[12] 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.

Of the 120 North Jersey residents who were placed in other developmental centers, two or 1.7% moved in Year 5. One of the residents moved once to a skilled nursing facility from a developmental center and one individual moved from a developmental center into the community.

One individual moved into the community during the report period from a skilled nursing facility. This individual initially moved from North Jersey DC to the community, then to a skilled nursing facility and was moved back into the community during Year 5.

None of the community individuals were admitted to a state psychiatric hospital during Year 5.

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 habilitative therapies as available options.[13]

The amount of staffing in community placements varied depending on the number and needs of the individuals in the placement. To examine the staffing at these community placements, a random sample of 17 community placements was selected.[14] The weekly per capita hours of direct service staffing averaged 77.4 with hours that ranged from 48.0 to 107.5 hours per person per week.

The number of direct care staffing hours was correlated with the number of individuals living in the home.[15] Most programs planned for minimal staff during weekday day-time hours from about 7 am to 3 pm when individuals were expected to attend day activities elsewhere. Conversely, programs kept higher staffing levels on weekends when residents were present all day and might leave the residence for shopping, lunch or social or recreational activities. In the event

[13] 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). Effective November 1, 2017, the Division's 1915(c) Community Care Waiver (CCW) was incorporated into New Jersey's larger and more wide-ranging 1115(a) demonstration waiver, known as the Comprehensive Medicaid Waiver, and was re-named the Community Care Program**.**

[14] Every individual was assigned a random number and the seventeen largest was selected and the program descriptions for their community facilities reviewed.

[15] Pearson correlation = .717

that a client is sick and unable to attend their day program, staffing is provided; similarly, additional staff is hired on an as needed basis for special activities or to ensure adequate coverage.[16]

Of the 161 residents in community placements[17], all but eleven 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 Plan. 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 forty-one of the 149 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.

Table 5 Types of day activities

Day Activity	N	%
DDD-Funded Adult Training (various types)	141	87.6
State Plan Funded Medical Day Programs	4	2.5
Senior Care	1	0.6
Mental Health Day Programming	3	1.9
Competitive employment	1	0.6
In-home supports[18]	11	6.8
Total	161	100.0

Four individuals participated in State Plan Medicaid-funded medical day programs offering "medical, nursing, social, personal care and rehabilitative services" along with lunch and transportation to and from the program. One individual was in senior care and three individuals were attending mental health day programming. One person was engaged in competitive employment.

Of the eleven individuals who did not participate in a formal external day program, five were retired and only participated in informal in-home supports. The remaining six individuals were not engaged in day activities at the start of the year due to various reasons.[19]

The Community Care Program provides transportation between the individual's residence and the location of the day habilitation service as a component part of habilitation services.[20] Adult

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[16] Information came from the program contract obligations and not observation of actual staffing on a day-to-day basis.

[17] Two individuals were in the care of DCF and were not included in this analysis.

[18] Individuals were not participating in day programming due to various reasons such as retirement, changing medical or behavioral needs or by choice.

[19] See footnote 18.

[20] See Section 17.6 Day Habilitation of Community Care Program Policies & Procedures Manual https://www.state.nj.us/humanservices/ddd/documents/community-care-program-policy-manual.pdf and Section 17.7 Day Habilitation of Supports Program Policies & Procedures Manual https://www.nj.gov/humanservices/ddd/documents/supports-program-policy-manual.pdf

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 and community care residences 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."[21] The Administrative Code further requires that documentation of visits be maintained in the consumer's record.

Information regarding routine medical care was obtained from the DDD's electronic records and group home staff.[22] Annual physical dates were unavailable for 26 individuals.[23] Analysis showed that 127 of 137 individuals or about 92.7% had an annual medical examination during Year 5. Of the ten individuals who did not receive a routine medical examination, three passed away before their scheduled annual examination date, two were transferred to skilled nursing or admitted to a hospital the time of their scheduled annual exam and five annual exams were completed just before and after the report period.

The licensing standards for residents of group homes as set forth in New Jersey's Administrative Code[24] 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), DDD's electronic records and calls to group homes. Procedure codes associated with dental claims for oral examinations and treatment were identified by the Division of Medical Assistance and Health Services' Dental Director and used in the analysis.

A total of 124 individuals or 79.0% of the 157[25] in the community received an annual dental care examination during Year 5. Eighteen individuals had Medicaid claims for some dental procedures, albeit not an annual oral examination. Fifteen had no Medicaid dental claims during the Year 5

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

[22] Due to the transition to support coordination and migration from the ALA tool to a new monitoring tool and service plan, annual physical dates for some individuals were unavailable. Calls and visits to group homes in the spring and summer of 2020 were adapted to collect annual physical dates. The change in data sources results in lack of comparability between prior reports.

[23] Reasons included not receiving services through DDD at the time of data collection, missing documentation and change in providers.

[24] Ibid.

[25] Six former residents living in the community did not have a dental claim and documentation was not available for various reasons including not receiving DDD services at the time of data collection, missing documentation and change in providers.

report period. In seven of the fifteen instances, documentation of dental examinations was found in electronic records or documentation was given by group home staff, but not a Medicaid claim. There were eight individuals with no Medicaid claims or documentation of a completed dental exam during Year 5. Common barriers are typically hospitalizations, guardian perference and behaviors that necessitate sedation; when medical conditions, such as seizure disorders, preclude safe sedation, it may be difficult to obtain medical clearances for dental procedures or reschedule appointments. Two of the eight individuals had exams completed shortly after the report period ended.

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.[26] In these situations, Emergency Medical Technicians (EMTs) and police typically respond, but the individual, depending on circumstances may or may not be transported to an emergency room, because not all Danielle's Law coded-incidents or incidents where 9-1-1 was called involve life-threatening emergencies as subsequently determined by medically trained personnel. 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.[27]

During Year 5, seventy-two individuals, or 44.2% of the 163 individuals living in the community, had one or more incidents that triggered a 9-1-1 call in compliance with Danielle's Law.[28] There were a total of 166 Danielle's Law incidents. 83.7% of the incidents were medical in nature while 27, or 16.3% were behavioral.

[26] See https://www.nj.gov/humanservices/ddd/providers/providerinformation/danielle/

[27] In place of the previously used UIRMS, the New Jersey Incident Reporting Management System, (NJIRMS) was rolled out on July 9, 2018. In the new NJIRMS, a Danielle's Law code was no longer used, and instead a "911 called" box was utilized. Then on September 25, 2018 in order to track incidents more accurately in NJIRMS, a life threatening emergency box was also added. The addition of both boxes helps more accurately indicate what incidents fall under Danielle's Law, because not all 911 calls are necessarily for life threatening emergencies. The number of incidents reported during this period should not be compared to previous reporting periods due to this change.

[28] Compared to 64.2% in the Initial Period from 7/1/13 to 6/30/15, 56.2% in Year 2, 55.7% in Year 3 and 50.3% in Year 4.

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. Of the 162 residents living in community placements with Medicaid claims, 114, or 70.4%, had emergency room visits during Year 5. The number of visits ranged from one to more than ten, with a mean of 3.9 (among those with visits). The most common reason given for the emergency room visit was a head, scalp or related injury, abrasions, contusions and lacerations; psychiatric or behavioral conditions; and other injuries, abrasions, contusions, lacerations, fractures or sprains not involving the head.

Table 6 ER visits during Year 5

# of ER Visits	N	%
0	48	29.6%
1	27	16.7%
2	30	18.5%
3	18	11.1%
4	9	5.6%
5	7	4.3%
6	5	3.1%
7	4	2.5%
8	3	1.9%
9	3	1.9%
10	2	1.2%
11+	6	3.7%
Total	162	100.0%

Table 7 Top 3 reasons for ER visits

Reason for ER visit	N
Head, scalp and related injuries, abrasions, contusions and lacerations	92
Psychiatric and behavioral conditions	71
Other injuries, abrasions, contusions, lacerations, fractures or sprains not involving the head	56

Of the 162 former North Jersey residents who were living in the community with Medicaid claims, 48 or 29.6% had one or more hospitalizations for medical conditions[29]. Community residents had a total of 101 hospitalizations. Leading reasons for hospitalization included urinary tract infections and other urinary conditions, gastrointestinal conditions and psychiatric and behavioral disorders.

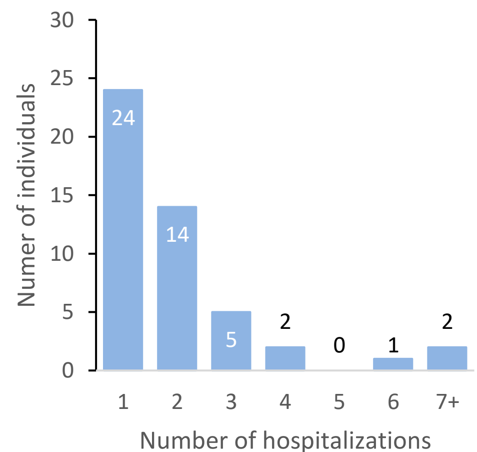

Figure 3 Number of hospitalizations in Year 5

[29] It should be noted that each hospitalization could result in more than one claim if the length of stay continues into the next month.

Table 8 Top 3 reasons for hospitalizations

Reason for hospitalizations	N
Urinary tract infections and other urinary conditions	13
Gastrointestional and digestive conditions	12
Psychiatric and behavioral conditions	11

Outcomes

This study examined a variety of outcomes for the individuals placed in the community. Where feasible, comparisons were made to individuals transferred to other developmental centers. 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?

New Jersey Comprehensive Assessment Tool

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 (NJCAT) is used annually to assess the placement cohort regardless of their residential setting.[30]

Assessments include composite scale scores for cognition and self-care and a single item that captures mobility. There are also summary levels 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 for Year 5 and compares scores for individuals placed in the community to those placed in other DCs. Data were available for 139 of the 163 community residents and 107 of the 120 DC residents. Within group comparisons were also made between Years 1/2 and 5,[31] including determination of statistically significant differences in these scores

[30] 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.

[31] One assessment was conducted in Years 1/2.

between those who were in DCs in both Years 1/2 and 5 (n=107) and those who were in community placements in both years (n=102). For this final report, individuals who did not move and completed NJCAT's for Years 1/2, Year 3, Year 4 and Year 5 were used to determine changes over the five years. There were 107 individuals living in other developmental centers and 95 individuals living in the community with NJCAT's completed for all 5 years of the study.

The cognition scale consisted of 21 items. Responses were either "yes" or "no." Scores could range from 0 for individuals who were unable to complete any of the tasks to a maximum of 21 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 4.88 (n=139) and for the DC residents was 4.84 (n=107).

Due to the wide dispersion and skew of the scores, the average is not a valid measure of the central tendency or a basis of comparison. The distributions in Figure 4 show that the majority of residents both in the community and the developmental centers had scores of zero or one.

Given the substantial skew in cognition scores, the analysis utilizes a dichotomous variable that captures whether or not the cognition scores reflect a substantial limitation. According to NJCAT documentation, summary scores of less than 18 on the cognition scale indicate a substantial limitation while scores at and above that threshold indicate no substantial limitation. Data (see Table 9) show that most of the individuals have a substantial limitation with negligible differences between the DC and community residents. Analysis shows that differences between community and DC scores were not statistically significant.[32]

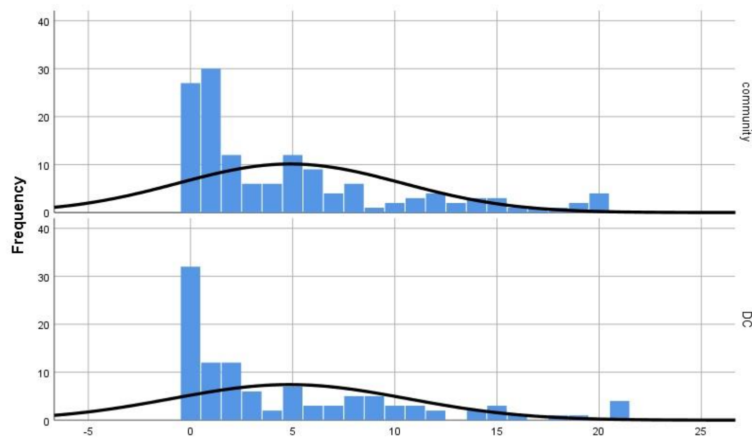

Figure 4 Cognition scores of community and DC residents, Year 5

Table 9 Percentage with a cognitive limitation by type of residence

Limitation	Community	DC
No substantial limitation	5.0%	5.6%
Substantial limitation	95.0%	94.4%

[32] Significance was based upon calculation of the chi-square statistic for a two-by-two table.

Comparisons between Year 1/2 and Year 5 cognition scores for individuals in the community and DC could not be made due to the majority of individuals scoring on the lower end. As shown in Figure 5, cognition scores for the community were higher than the DC scores in Year 1/2 and trended downward from an average of 5.33 in Year 1/2 to 3.89 in Year 5. The DC scores remained fairly constant. Examining the year to year differences, the major contributer is the change between Year 1/2 and Year 5. The community scores varied significantly[33] year to year while the DC cognition scores did not. Examining the year-to-year differences in community scores, the major contribution is the change between Year 1/2 and Year 5.

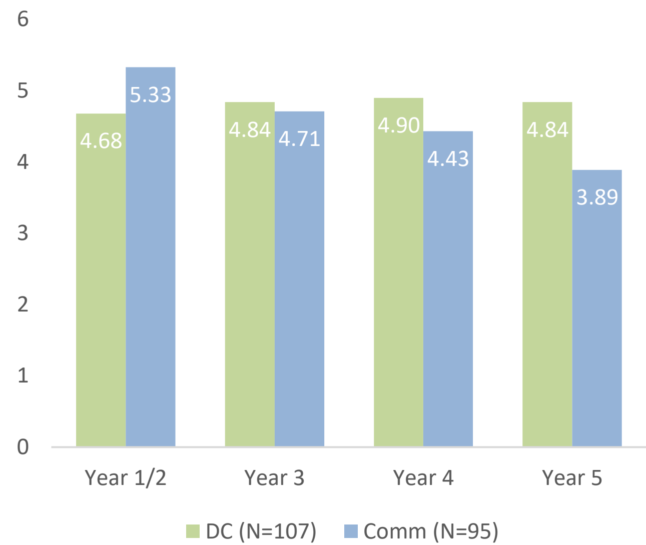

Figure 5 DC and community average cognition scores over time

The basic self-care need scale 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.

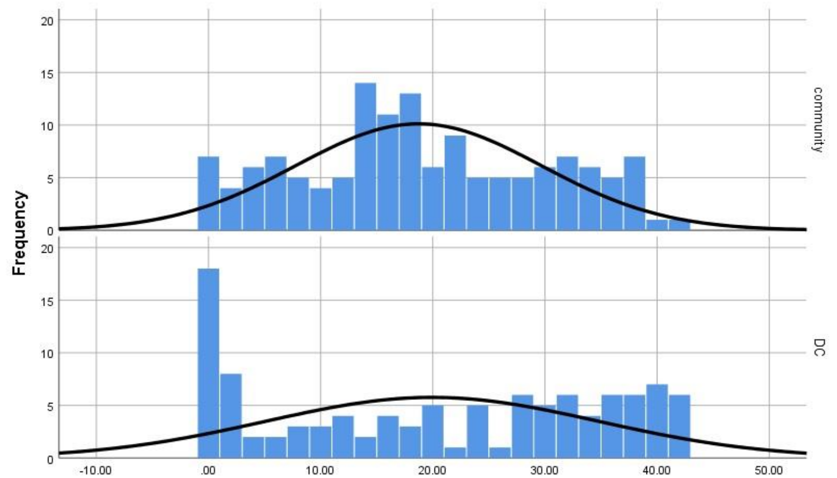

Figure 6 Basic self-care scores of community and DC residents, Year 5

[33] Significance was based upon calculation of a Greenhouse-Geisser repeated measures ANOVA, sphericity not assumed.

The average scale score for community residents was 18.7. The DC residents' mean was slightly higher at 19.9. While there is considerable skew in the DC scores, the standard deviation does not exceed the mean and thus comparison of means are feasible for significance testing. Results show that the difference between the mean self-care scores for the community and DCs are not statistically significant.[34]

A comparison of Years 1/2 and 5 showed a statistically significant decrease in self-care scale scores for community residents. The DC residents did not show a statistically significant difference in self-care scale scores over time. When comparing means over time, the community showed a significant difference between Year 1/2 and each year there after[35]. The community scores started higher than the DC scores at 24.23 and declined to an average of 17.71 in Year 5. The DC scores remained fairly constant and showed no significant differences over the study period.

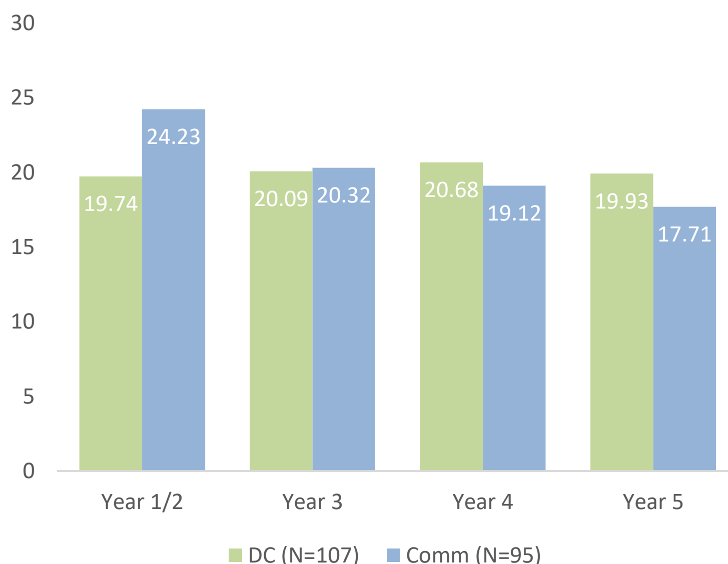

Figure 7 DC and community average basic self-care scores over time

This question captured mobility: *"Does (name) walk independently without difficulty, without using a corrective device, and/or without receiving assistance."* Analysis of Year 5 data shows 42.4% of the community residents and 46.7% of the DC residents were able to walk independently. Differences between the community and DC cohorts were not statistically significant.[36] Comparisons of Year 1/2 and Year 5 mobility scores show that fewer individuals walk independently in Year 5 in the community, 62.7% in Year 1/2 and only 39.2% in Year 5. These differences were statistically significant[36]. By contrast in the DC, 46.7% walked independently in Year 1/2 and in Year 5. Though the percentage of individuals who walked independently remained the same, there were 6 individuals who improved and 6 individuals who declined. These changes in mobility were statistically significant[36].

[34] T-test of difference of means for independent samples where equal variances are not assumed.
[35] Significance was based upon calculation of a repeated measures ANOVA, sphericity assumed.
[36] Significance was based upon calculation of the chi-square statistic for a two-by-two table.

Consumer Interviews

Research staff interviewed consumers in order to determine their satisfaction with residential placements and whether they would prefer to return to a developmental center. Interviews with former residents aren't appropriate in every case. For the purposes of this study the authors determined that interview subjects should, at a minimum, be able to make comparisons and recollect past experiences. Four items from the most recent NJCAT evaluation were the criteria that had to be met in order for an individual to be selected: the ability to remember events that happened a month or more ago; the ability to understand the difference between yesterday, today and tomorrow; the ability to use a few simple words, signs or picture symbols; and finally, the ability to understand a joke or story.[37]

Many residents had significant cognitive impairment and could not be interviewed. Of the original community placements, nineteen were determined eligible to be interviewed based on the NJCAT evaluations or were interviewed in prior years. An additional seventeen individuals initially placed in other developmental centers but subsequently given community placements were also eligible for interviews. One individual could not complete the interview due to cognitive or other limitations. One interview was incomplete due to the individual ending the interview before the residential preference was discussed. A total of nineteen interviews were successfully completed[38]. The residents were asked what they liked and disliked about their lives in their current residence, and where they would prefer to live if given the choice: their current residence, NJDC, a different community residence or somewhere else.

Table 10 Consumer interviews: eligibility and completion

Population	Eligible (NJCAT)	Able to Complete
Original Community Placement	19	9
DC to Community	17	10
Total	36	19

Among the nineteen reliable community residents who were interviewed about their housing preferences, eleven preferred their current residence. The reasons they gave often had to do with the staff and housemates, weekend outings, proximity to family resulting in more frequent contact, satisfaction with day programming, meals, and less noise. One individual stated "I want to stay where I'm at. All of my friends are here, I want to stay with them… I was too far away from my family, too far from my [family member]." Another individual said, "My life is heaven… I have staff that care about me. I have a good roommate that loves me… I live near nice people,

[37] The individuals identified using the first year NJCAT scores were interviewed for the third, fourth and fifth year.

[38] The interview schedule typically begins in January and concludes in May. Interviews for Year 5 began in January 2020 with twenty one interviews attempted before the Division directed all facility-based day program settings to close and provider-facilitated community outings to be discontinued to mitigate the spread of COVID-19 on March 13, 2020. Restrictions and precautions continued well into the fall of 2020 and in order to minimize exposure and maintain interview format, fifteen interviews were not conducted.

a lot of stores where I can shop at. I live near my [family member]" Former NJDC residents talk about having laptops, televisions, various collections, crossword puzzles, toys and games, basketball hoops, radios, movies, going out to eat, shopping, bowling allys and movie theaters, as well as having family members visit or visiting them at their homes. In some cases, they not only recall positive experiences in the community, but negative experiences in the developmental center. One person said with reference to NJDC, "I don't want to go back to North Jersey ever again."

One individual shared positive recollections of North Jersey and were open to returning to NJDC. This individual shared ongoing conflicts with a housemate and when asked specifically what they prefer about NJDC they said "the snacks". One individual did not have a preference in living arrangements. When asked their preference they said "both places." The individual liked having their own bedroom and shared that they enjoy the outings and holiday celebrations and gifts at their current residence. When asked if they like their program they said "Yes, I do. I like everything." One individual who ultimately preferred to live somewhere else in the community explained the convience of having doctors on the campus of NJDC as a positive aspect of his experience at the developmental center.

Six individuals wanted to live somewhere else and of those, two have since moved. Among those who wished to live somewhere else, wanting to live with or in closer proximity to family or day programs, housemate conflicts or desire to live more independently and with fewer housemates. Preferences were apartments or group homes closer to family members and day programs.

It should be noted that perceptions about living arrangements and day programs were independent of one another. People could love their day program and dislike their residential setting and vice versa. Some individuals expressed the desire to engage in paid employment both for the opportunity to have work experiences and to be more active.

Family Contacts

Information about contact community residents have with family was obtained from the family/guardian surveys and staff members from individual's residences. There were 18 of 163 individuals who had missing or invalid data. Of the 145 with information regarding family, results show that 20 had no involved family.

Table 11 Family involvement among community residents

Family involvement	N	%
Family involved	125	86.2%
No family	20	13.8%

Of the remaining 125 with family and information regarding the frequency of contact, 25 had no contact with family. Of the 100 with at least annual contact, 56 had at least weekly contact; 29 had at

least monthly contact; 10 had at least quarterly contact; 5 had contact at least once during the year.

Of the 163 community residents, data regarding access to peers were available for 142 individuals. 138 out of 142 individuals, or 97.2% had access to peers. Frequency of contact with peers amongst this group was primarily on a daily basis.[39]

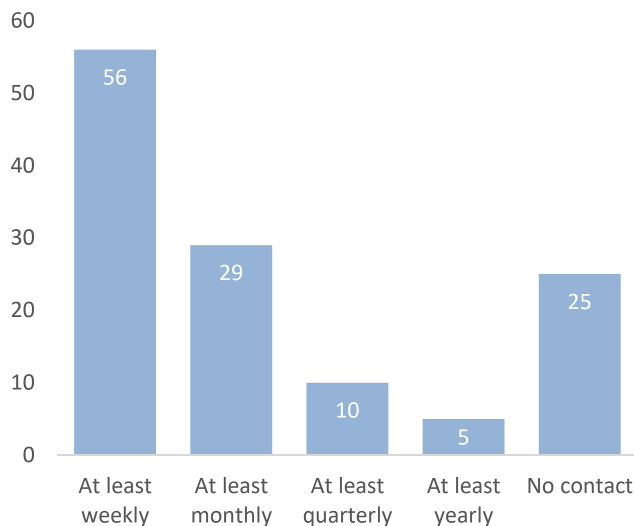

Figure 8 Frequency of family contact during reporting period (N= 125)

Year 5 Family/Guardian Survey: Community Residents

The study also incorporated the perspectives of private guardians about the North Jersey cohort's quality of life in the current residence. A survey[40] was mailed to the family/guardians of everyone (n=76) who had been placed in the community, had private guardians (i.e., family members, friends, or advocates), and were still residing in the community at the time of the survey. Family/guardians who did not respond to the initial mailing received a postcard reminder followed by up to three phone calls.

As of August 13, 2020, 58 surveys had been received from 95 family/guardians. These 58 responses included four residents with two family respondents each; one survey for each consumer was chosen at random, leaving 54 surveys and a response rate of 71.1%. Fifty respondents (92.6%) were related to the former North Jersey resident, while four were unrelated private guardians (7.4%). Relatives were primarily either siblings (61.1%) or parents (25.9%). Other family members included a grandparent and niece or nephews (5.6% combined).[41]

Most (81.5%) of the respondents (n=44) had visited former North Jersey residents in their community placements. Fifty-three out of fifty-four (98.1%) individuals had some form of contact

[39] Comparisons between previous report periods and Year 5 were not made due to new data sources beginning in Year 3 resulting lack of comparability.

[40] See Appendix. Items were based upon surveys conducted of previous institutional closures in New Jersey.

[41] Changes in guardianship relationships from previous year's report may reflect differences in who responded to the survey.

with their loved one. Nineteen respondents contacted staff at the residence. Twenty-four respondents had contact with residents by phone or email. The totals summed to more than 54, because respondents could have multiple methods of contact. For example, eighteen individuals both visited and had contact via phone or email. Of the nineteen respondents who contacted staff, twelve also visited the residence. There were eleven respondents who visited the resident, contacted staff at the residence and contacted the resident by phone or email.

Each respondent was asked about his or her perceptions of the relatives' quality of life. Respondents could answer indicating their degree of happiness or satisfaction with varied aspects of quality of life. Numbers were assigned to the ratings such that higher scores indicated a more positive rating, while lower scores represented a more negative rating for the item. Each respondent was also asked to provide an overall rating regarding how his or her relative is doing in the 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.

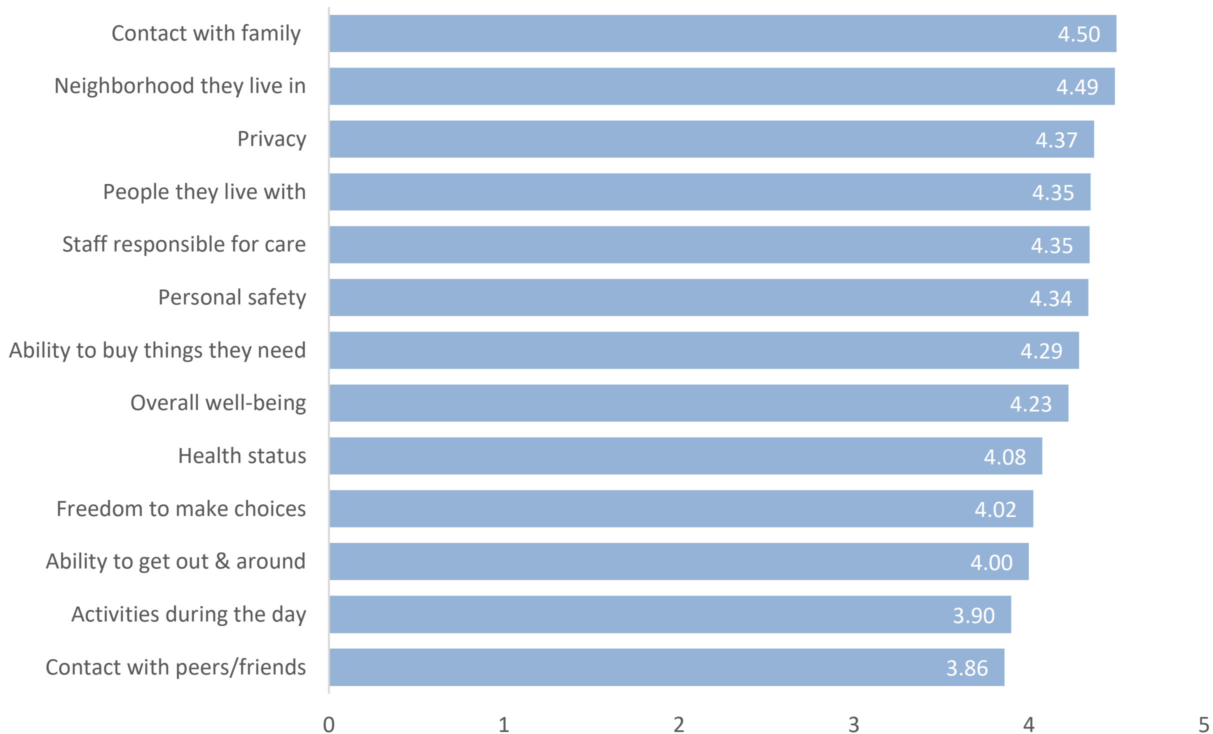

Figure 9 Family guardian perceptions of consumer's current living situation

Average scores for 11 of the 13 items exceeds a 4 with most items falling between 4 and 5 (indicative of being between somewhat happy to very happy).[42] Guardians were happiest with the family contact, neighborhood where their relative resides, and the relative's privacy. They were least happy with the contact they have with peers and friends.

Each respondent was also asked to indicate satisfaction with each of seven aspects of community programming for his or her relative, 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.

High reported satisfaction in programming and services as shown in Figure 10 was evident in the item averages, which ranged from a low of 4.14 to a high of 4.52, where a 5 indicates the respondent is very satisfied. The rating for average satisfaction with transportation to appointments or programs at 4.52 was the highest for any of the community programming ratings.

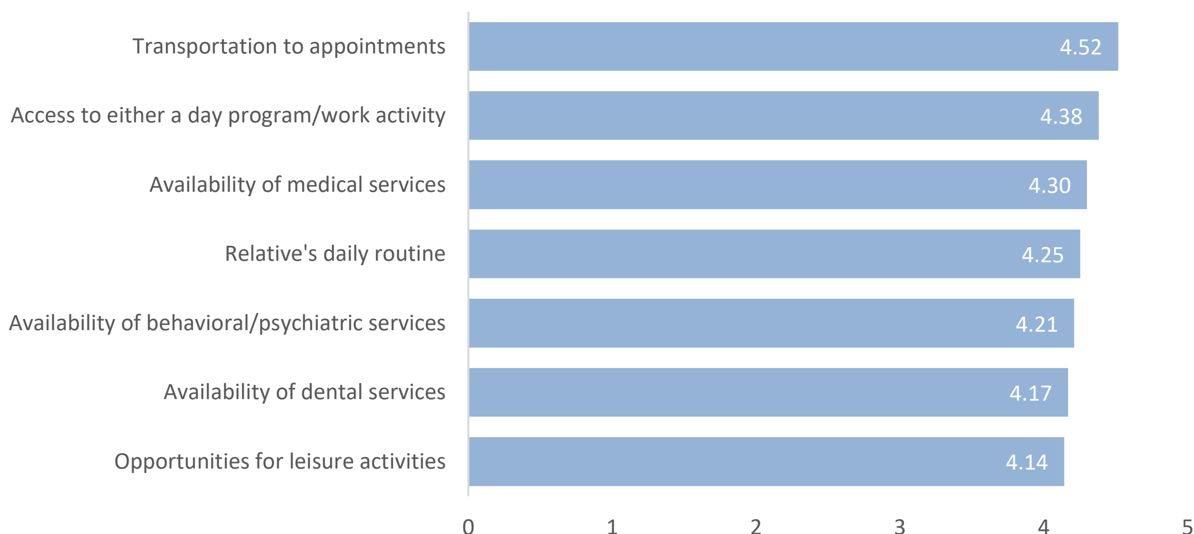

Figure 10 Average ratings of programming and services (higher scores indicate greater satisfaction)

Community guardians were asked to rate their relatives well-being in their current living arrangements compared to when they lived at North Jersey Developmental Center. Ratings were assigned scores as follows: "significantly improved"= 5; "somewhat improved" = 4; "unchanged" = 3; "somewhat declined" = 2; and "significantly declined" = 1.

Forty-two out of fifty-four (77.8%) guardians rated a significant or somewhat improvement in their relatives well-being. Five (9.3%) guardians rated their well-being unchanged and five (9.3%) rated somewhat or significant decline. Two (3.7%) guardians left the question blank. Guardians

[42] The legislation specifically mentions personal safety and health status, both of which are rated over 4.0.

average change in well-being was between somewhat improvement and significant improvement, with an average score of 4.27.

Table 12 Community guardian perception of relative's change in well-being compared to North Jersey DC (n=54)

Change in well-being	N	%
Significant/somewhat improved	42	77.8%
Unchanged	5	9.3%
Significant/somewhat declined	5	9.3%
Don't know/Missing	2	3.7%

Year 5 Family/Guardian Survey: Community and DC Comparisons

A comparison was made between the perceptions of overall quality of life of private guardians of the North Jersey residents in community placements to the private guardians of individuals from North Jersey who were transferred to other developmental centers. In order to make this comparison, surveys were mailed to the family/guardians of everyone (n=68) living in a developmental center, who had private guardians (i.e., family members, friends, or advocates), and were residing at the developmental center at time the survey was conducted.

Family/guardians who did not respond to the initial mailing received a postcard reminder followed by up to three phone calls. As of August 13, 2020, 52 surveys had been received from 98 family/guardians. These included four residents with two family respondents each; one survey for each consumer was chosen at random, leaving 48 surveys and a response rate of 70.6% for the 68 DC residents. Forty-six out of forty-eight (95.8%) of the respondents were family members, primarily siblings (43.8%) or parents (29.2%); Five of the respondents (10.4%) were cousins, three (6.3%) were grandparents, and two respondents (4.2%) were aunts/uncles. One respondent was a niece/nephew (2.1%).

Asked to rate how their relative is doing overall. 41 of 54 (75.9%) guardians of community residents and 42 of 48 (87.5%) guardians of other developmental center residents reported their relative was doing "Excellent" or "Good." Twelve (22.2%) guardians of community residents and five (10.4%) guardians of residents of other developmental centers rated their relative as doing "Fair/Poor." One (1.9%) guardians of community residents and one (2.1%) guardian of a resident in another developmental center did not answer the question or responded "don't know."

Table 13 Guardian perception of relative's well-being

How relative is doing overall	Community (n=54)	DC (n=48)
Excellent/Good	75.9%	87.5%
Fair/Poor	22.2%	10.4%
Don't know/Missing	1.9%	2.1%

Comparisons between the perceptions of family/guardians of community and DC residents were also made with regard to their happiness with various aspects of quality of life and their satisfaction with community programming. Family guardians of DC residents were significantly happier (or less apt to be unhappy) with the activities their relatives had access to during the day, staff responsible for their care, and overall well-being. Family guardians of DC residents were significantly less worried about the preparation of staff to handle behavioral or medical problems. Family guardians of DC residents were significantly more satisfied with the availability of behavioral/psychiatric services.

Table 14 Changes to individual's situation over the past year

	Community (n=54)		DC (n=48)	
Types of changes	N	%	N	%
Has different staff caring for him/her	27	50.0%	18	37.5%
Moved to a different residence	4	7.4%	8	16.7%
Has a different roommate	8	14.8%	9	18.8%
Attends a different day program	10	18.5%	---	---

Each guardian was asked to identify, to the best of his or her knowledge, changes to their relative's situation over the past year. Guardians of community residents reported that the most frequent change was in staff caring for the relative (50.0%) and the least frequent change was moves to a different residence (7.4%). Guardians of developmental center residents also reported that the most frequent change was in staff caring for the relative (37.5%) and the least frequent change was moves to a different residence (16.7%).

Family/Guardian Survey: Year 1/2 and Year 5 Comparisons

The results from surveys of family guardians who completed a survey for both the Year 1/2 and the Year 5 report periods were compared. There were 33 family members of individuals living in DCs and 37 from the community who responded to the survey both years of the study. Because of these small sample sizes, statistical significance cannot be determined. As such, the following results are purely descriptive. As noted throughout, even in situations where satisfaction has decreased, the average scores are still, at a minimum, in the positive categories, ranging primarily from happy to very happy.

Table 15 Comparison of average family guardian ratings of happiness with aspects of current living arrangement, Year 1/2 and Year 5.

	Community (n=37)				DC (n=33)			
Community & Social Interaction	**Year 1/2 Mean**	**Year 5 Mean**	**Difference**	**N**	**Year 1/2 Mean**	**Year 5 Mean**	**Difference**	**N**
People they live with	4.32	4.44	0.12	34	4.26	4.30	0.04	23
Neighborhood they live in	4.61	4.53	-0.08	36	4.30	4.48	0.19	27
Privacy	4.52	4.39	-0.13	31	4.38	4.54	0.15	26
Personal safety	4.61	4.47	-0.14	36	4.45	4.35	-0.10	31
Contact with family	4.75	4.58	-0.17	36	4.67	4.22	-0.44	27
Staff responsible for care	4.67	4.42	-0.25	36	4.63	4.69	0.06	32
Health status	4.43	4.14	-0.30	37	4.35	4.52	0.16	31
Activities during the day	4.31	3.97	-0.33	36	4.44	4.68	0.24	25
Contact with peers/friends	4.37	4.04	-0.33	27	4.29	4.57	0.29	21
Overall well-being	4.56	4.22	-0.33	36	4.39	4.61	0.23	31
Ability to buy things they need	4.60	4.25	-0.35	20	4.37	4.53	0.16	19
Freedom to make choices	4.43	4.04	-0.39	23	4.18	4.47	0.29	17
Ability to get out and around	4.56	4.00	-0.56	34	4.11	4.36	0.25	28

Note: Sample sizes vary by item due to variations in item response; the term, “mean” is synonymous with the average score.

Each guardian rated his or her happiness with several quality of life domains. Answer choices were on a five-point scale where high scores were more positive. Community guardians rated the people they live with more highly in Year 5 than Year 1/2. The remaining ratings decreased four years later. Despite these numeric decreases, ratings primarily fell between somewhat happy and very happy.

DC guardians rated eleven of the thirteen items higher in Year 5 than Year 1/2. The most improvement in happiness was reported for the consumers’ freedom to make choices, contact with peers and friends and ability to get out and around. The people they live with improved among family/guardians of consumers in both the community and DCs. Conversely, perceived happiness with contact with family and personal safety declined in both placement settings.

Table 16 Comparison of average family guardian ratings of satisfaction with aspects of current living arrangement, Year 1/2 and Year 5.

	Community (n=37)				DC (n=33)			
	Year 1/2 Mean	**Year 5 Mean**	**Difference**	**N**	**Year 1/2 Mean**	**Year 5 Mean**	**Difference**	**N**
Opportunities for leisure activities	4.27	4.24	-0.03	33	4.58	4.65	0.08	26
Availability of behavioral or psychiatric services	4.38	4.34	-0.03	32	4.67	4.75	0.08	24
Access to either a day program or work activity	4.53	4.38	-0.15	34	4.59	4.59	0.00	22
Availability of dental services	4.53	4.38	-0.15	34	4.56	4.56	0.00	25
Relative's daily routine	4.44	4.28	-0.17	36	4.70	4.70	0.00	23
Transportation to appointments or programs	4.83	4.53	-0.31	36	4.44	4.52	0.07	27
Availability of medical services	4.70	4.35	-0.35	37	4.80	4.63	-0.17	30

Note: Sample sizes vary by item due to variations in item response; the term "mean" is synonymous with the average score.

Each family guardian rated his or her satisfaction with aspects of the resident's programming, including access to medical, dental and behavioral health services, transportation, day program, and daily routine and leisure. Average ratings for Year 5 were compared to Year 1/2. All averages for Year 5 across all aspects of services were rated between somewhat satisfied and very satisfied by both the community and DC guardians. Community guardians rated all of their relatives' services lower the fifth year than the first and second years responses. The DC guardians rated opportunities for leisure activites, availability of behavioral/psychiatric services and transportation to appointments or programs higher the fifth year. The DC guardians rated availability of medical services lower in Year 5, while access to either a day program or work activity, availability of dental services and daily routine remained the same.

Community and DC guardians rated how their relatives were doing overall in their current living arrangements. Ratings were assigned scores from 1 (poor) to 4 (excellent). Guardians who responded "Don't know" were excluded from this analysis. The community rating decreased by 0.11 and the DC average decreased by .06.

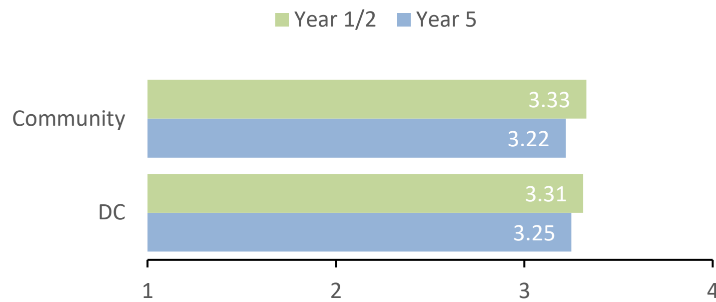

Figure 11 Average community (n=36) and DC guardian (n=32) overall ratings of current living situation by reporting year.

Health Status

The study also examined health status outcomes such as the need for medical and behavioral health supports and mortality. Information regarding the need for medical and behavioral supports was obtained from the NJCAT tool.

The measure of the need for medical supports considers three levels of medical need.[43] As shown in Figure 12, both populations predominantly need specialized medical care, but compared to the community residents, a greater percentage of DC residents need the more intensive specialized on-site nursing care. These differences are statistically significant.[44]

Among community residents present in Year 1/2 and Year 5 (n=102), medical supports scores could not be tested for statistical significance mostly due to the small number of residents in the community both years who needed specialized on-site nursing.

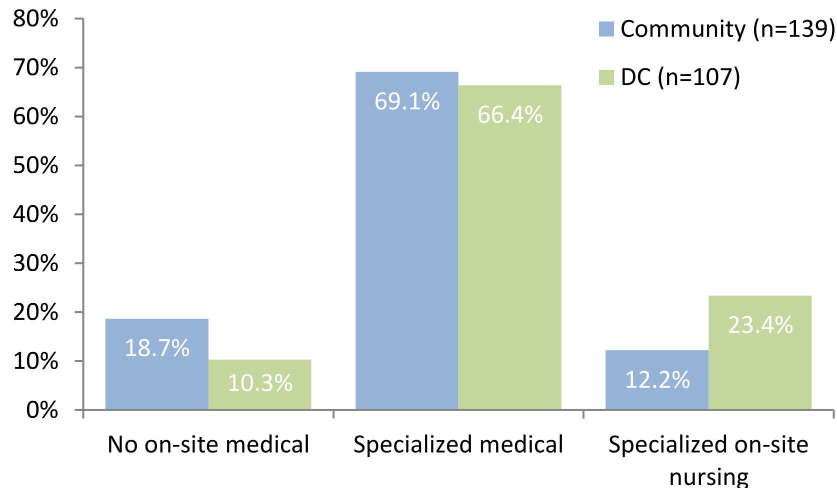

Figure 12 Medical assistance by residential placement type, Year 5

[43] 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.

[44] Per analyses using Pearson's chi-square significant at .05 or less.

Nonetheless, tendencies are apparent in the data. The percentage of individuals needing no on-site nursing dramatically decreased by 17.6 percentage points. This resulted in an increase of 9.8 percentage points in specialized medical and a 7.9 percentage point increase in specialized on-site nursing.

The DC residents' medical supports scores also could not be tested for statistical significance from Year 1/2 to Year 5 (n=107). The categories with the largest change was no on-site medical with a 4.7 percentage point decrease and a 2.8 percentage point increase of specialized medical.

The Behavioral Supports Level has scores ranging from 1 to 4, with higher scores associated with behaviors requiring more intensive support and environmental modifications.[45]

A comparison of data for community and DC residents shows that a much larger number of community residents needed intensive behavioral health supports (53.2%). A sizable percentage (30.8%) of DC residents had no on-site behavioral health support needs compared to only 2.2% of community residents. Decisions regarding residential placements were made by the residents' guardians. Among those who selected to live in the community, behavioral health supports were more apt to be required than among those who moved to a developmental center. These differences were statistically significant.[46]

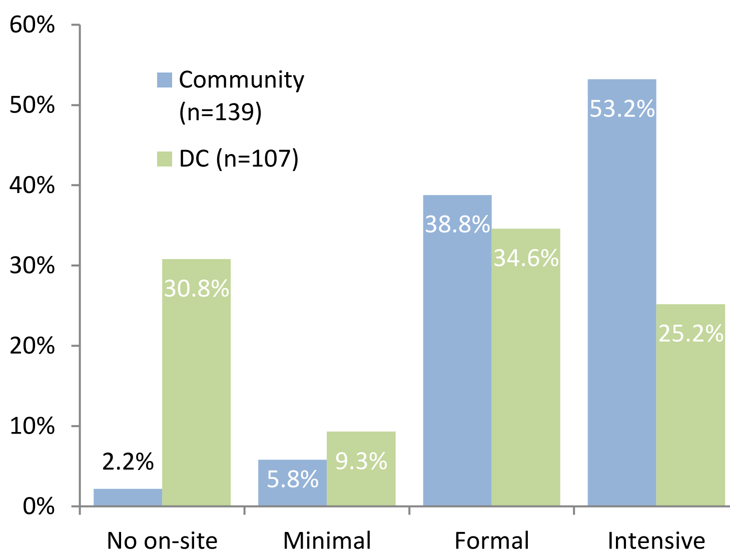

Figure 13 Need for behavioral supports by placement type, Year 5

Among community residents present in Year 1/2 and Year 5 (n=102), behavioral supports scores could not be tested for statistical significance due to the small number of residents in the community both years and all of the numerous potential changes each resident could experience. The category with the most change was intensive supports which increased by 15.7 percentage points; there was a corresponding 13.6 percentage point combined decrease in the number of

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

[46] Per analyses (using Pearson's chi-square).

individuals with no on-site and minimal behavioral supports. Formal behavioral supports also had a small decline of 1.9 percentage points.

The DC residents' behavioral supports scores also could not be tested for statistical significance from Year 1/2 to Year 5 (n=107). Changes were much less for community residents. The category with the largest change was intensive supports which decreased by 2.8 percentage points and no on-site supports which increased by 2.8 percentage points.

Mortality

Of the 163 individuals living in the community at the start of the report period, three (1.8%) passed away in Year 5. All three deaths resulted from natural causes[47] (Acute Hypoxic Respiratory Failure due to pneumonia, Failure to Thrive due to Dysphagia and Hypernatremia and Cardiopulmonary Arrest due to Coronary Artery Disease). None of the deaths resulted in an investigation.

Of the 120 individuals living in developmental centers, eight (6.7%) passed away in Year 5. All deaths resulted from natural causes. The specific causes of death were as follows:

- Cardiopulmonary arrest due to metastatic ovarian adenocarcinoma with malignant ascites, pleural effusion and COPD
- Acute Respiratory Distress Syndrome
- Respiratory failure
- Hypoxemic respiratory failure
- Aspiration pneumonia due to cerebral Palsy
- Respiratory Failure due to Chronic Respiratory Insufficiency of COPD, Bilateral Renal Lithiasis with sepsis and Down's Syndrome
- Cardiac Arrest due to hemodialysis fistula exsanguination and end stage renal disease
- Cardiorespiratory failure due to chronic pulmonary interstitial disease, chronic hypoxia, recurrent Urosepsis, recurrent pneumonia, sepsis, renal insufficiency, and congestive heart failure

Of the eight individuals living in a Skilled nursing facility at the start of Year 5, one passed away in Year 5. The individual initially moved to another developmental center from North Jersey DC and subsequently moved to a Skilled Nursing Facility. The manner of death was natural and the cause of death was cardiac arrest.

[47] As contrasted with accidents or homicides.

Unusual Incidents

The Department of Human Services' Incident Reporting and Management System (NJIRMS) 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[48]. 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 IRMS database include the incident code, date of the incident, the responding party, and the action taken. The documentation of law enforcement is not often standardized. 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 narratives. This review of UIRMS and NJIRMS data yielded seven incidents with law enforcement involvement.[49] There was a total of five former North Jersey DC residents involved in the seven incidents. Plans of correction were put in place and polices were appropriately amended to prevent future issues.

This concludes the final North Jersey DC closure evaluation for the fourth and final annual report (covering the fifth year post-closure).

[48] In July 2018, a new incident reporting system, NJIRMS was rolled out. In the old system, UIRMS, any time there was a report of a potential criminal act it was reported as criminal activity. In the new system, criminal activity is only used when charges are pressed. The number of reported incidents during this period should not be compared to other reporting periods due to this change in systems.

[49] Inividuals could be listed on an incident report if they were present during the incident but were not the victim or perpetrator.

Appendix: Family Guardian Survey

Family and Guardian Survey - North Jersey Developmental Center Residents in Community Placements - Year 5

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 to the community during the closure process. As part of its statutory requirement, DHS' Office of Research, Evaluation, and Special Projects is collecting data from various sources, including information from family members and/or guardians about former residents' 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 North Jersey Developmental Center 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. You may have been contacted in past years for previous post-closure surveys. Even if you did not receive the previous surveys, you can still complete this one. As stipulated in the legislation, this will be the final survey. Your answers should reflect your perceptions of how well your relative has done over the past year.

Please return your completed survey within two weeks in the stamped, addressed envelope provided.

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

Your feedback is important to us. Thank you for your participation!

Family and Guardian Survey - North Jersey Developmental Center Residents in Community Placements - Year 5

SURVEY

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

Your Name (Print):

Your Relative's Initials:

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

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

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

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

4. How frequently have you had contact with your relative in the past year? (Select the answer that best reflects the amount of contact)

- ◯ Daily
- ◯ Weekly
- ◯ Monthly
- ◯ Quarterly
- ◯ Annually
- ◯ No contact in the past year
- ◯ Other (please specify)

5. To your knowledge, has your relative's living situation changed in any of the following ways over the past year? (Check all that apply)

- ☐ Moved to a different residence
- ☐ Has a different roommate
- ☐ Has different staff caring for him/her
- ☐ Attends a different day program

Other (please specify)

6. Regarding your relative'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	◯	◯	◯	◯	◯	◯

7. How worried are you about each of the following at your relative'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)

8. 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	◯	◯	◯	◯	◯	◯

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

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

10. How would you rate your relatives well-being in the community *compared to* when they lived at North Jersey Developmental Center? (Select ONE)

- Significantly improved
- Somewhat improved
- Unchanged
- Somewhat declined
- Significantly declined

11. Would you like a staff member to follow up with you directly regarding any concerns indicated on this survey?

- Yes
- No

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

12. Do you have any additional comments? If yes, please specify (use the back of the page if necessary):

Thank you for your continued participation in the survey, your responses are valued and help DHS strengthen the quality of supports and services provided to constituents. Previous closure reports can be accessed at https://bit.ly/38ypHyP or paper copies can be requested by contacting

PLEASE RETURN YOUR SURVEY WITHIN TWO WEEKS IN THE STAMPED, ADDRESSED ENVELOPE THAT HAS BEEN PROVIDED.