

Woodbridge Developmental Center Year Two Closure Report

NJ DHS Office of Research, Evaluation & Special Projects

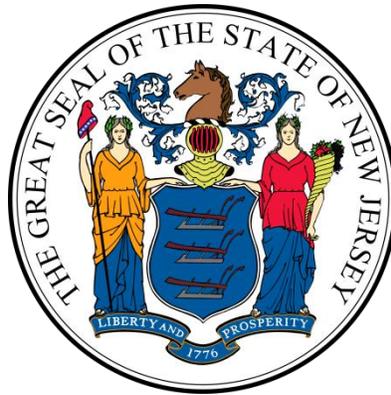


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Introduction

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 law⁴ 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 placement⁶ complicate year-to-year comparisons.

This report presents data for the second year following the closure of Woodbridge 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 2. As feasible and appropriate, contextual comparisons are made between consumers moved into

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/JSOImPlanFinal.pdf>

³ The Task Force’s final report is available here:

<http://www.state.nj.us/humanservices/ddd/documents/Documents%20for%20Web/Closure%20Task%20Force%20Report.pdf>

⁴ A-1098/S-671 (Vainieri Huttler, 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.

community placements and those residing in developmental centers. Information was obtained from a variety of sources and utilized methodologies including consumer and family surveys, specialized 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.

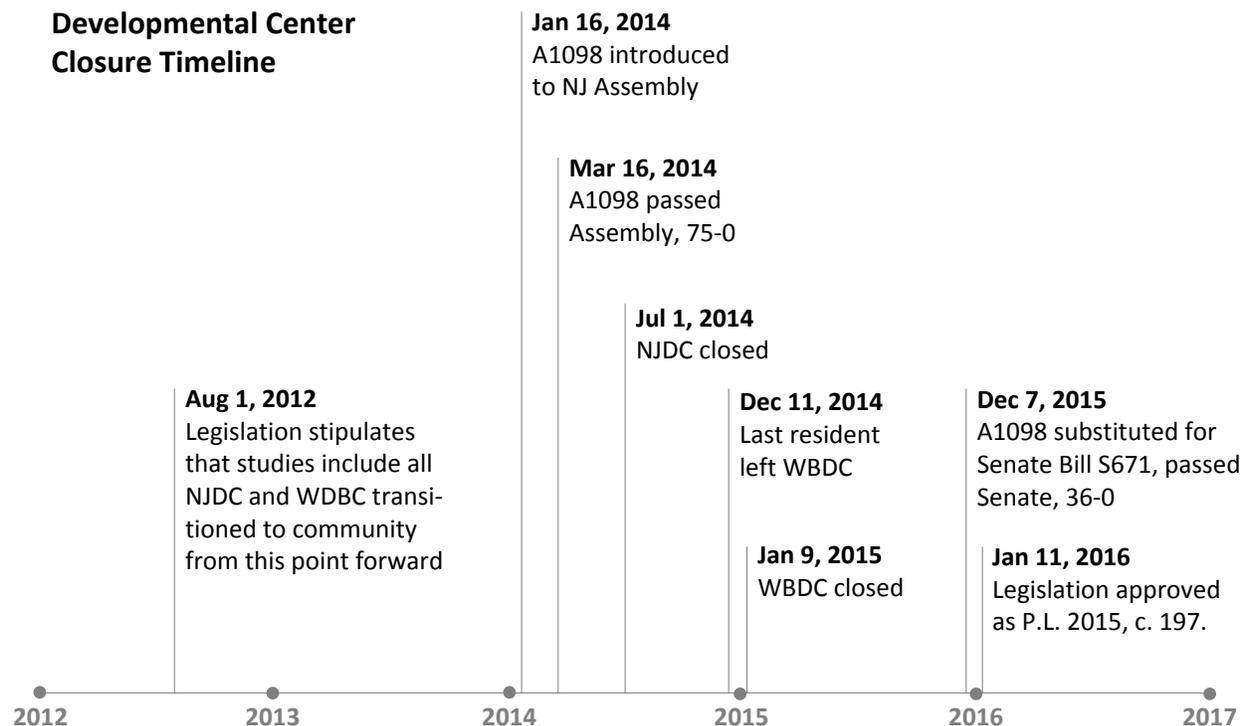


Figure 1 Timeline of DC closure

Woodbridge Developmental Center

The evaluation focuses on the 333 residents who were living at Woodbridge Developmental Center (WDBR) 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 December 2014. Woodbridge Developmental Center officially closed on January 9, 2015. The findings for this second report cover the period from January 8, 2016 until January 7, 2017. At the start of that time period, there were 295 members of the cohort. Thirty-eight individuals are not part of this report. Between August 1, 2012 and January 7, 2016, ten individuals passed away prior to moving from Woodbridge. Following placement, be-

Table 1 Cohort attrition

Cohort Attrition	Year 1	Year 2
Individuals at the start of the report period	333	295
Pre-placement deaths	10	--
Deaths	26	11
Discharges	2	11

tween August 1, 2012 and January 7, 2016, 26 passed away in developmental centers (n=20), community placements (n=4), and skilled nursing facilities (n=2). Two were discharged to family out-of-state so nothing is known of their status.

Residential Settings

At the start of the report period, there were 295 former Woodbridge Developmental Center residents living elsewhere in the state. A total of 212 individuals or 71.9% of the 295 former Woodbridge Developmental Center residents were residing in other developmental centers.⁷ Of the remaining 83 residents, 80 were living in the community.

Three residents were in Skilled Nursing Facilities (SNF). This report focuses on the 212 individuals residing in developmental centers and 80 persons living in the community.

Of the 212 individuals from Woodbridge who were living in Developmental Centers at the start of the report period, 50% resided in either Woodbine or Vineland. An additional

19.8% resided in New Lisbon and 16.0% and 14.2% were living in Green Brook and Hunterdon, respectively.

Persons

The 295 former WBDC residents who were cohort members in January 2016, were more likely to be male (58%) and

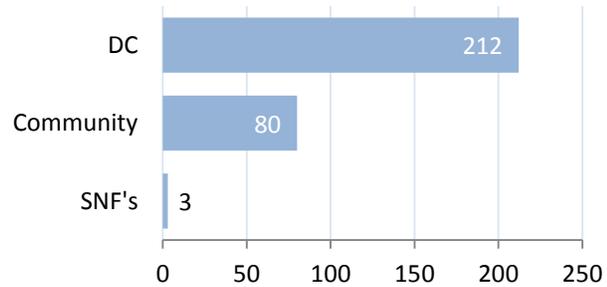


Figure 2 Placements from Woodbridge as of 1/8/2016 by type

Table 2 DC residents at start of report period by placement

Developmental Center	N	%
Woodbine	58	27.4%
Vineland	48	22.6%
New Lisbon	42	19.8%
Green Brook	34	16.0%
Hunterdon	30	14.2%
Total	212	100.0%

Table 3 Characteristics of Woodbridge Residents on January 8, 2016 (n=295)

Characteristics	Year 2
Gender	
Male	58.0%
Female	42.0%
Age Group	
22 - 44 years	7.1%
45 - 54 years	21.0%
55 - 64 years	51.9%
65+ years	20.0%

⁷ Guardians approve placement decisions and they request placement in another developmental center.

between 55 and 64 years old (51.9%). The mean age of the population was 57.6 years.

Placement decisions were approved by the residents' guardians. Of the 212 former residents of Woodbridge who were living in other developmental centers at the start of the second year of the study, 164 or 77.4% had private guardians, primarily parents⁸ and siblings, but also including aunts/uncles, cousins, and other family members. Less than one-fourth (46 or 21.7%) had state guardians; two consumers were their own guardian.

Table 4 Guardians of DC and community residents by study year

Guardian Type by Placement	Year 1		Year 2	
	N	%	N	%
Developmental Center	236		212	
Private (Family)	179	75.8%	164	77.4%
State Guardian	56	23.7%	46	21.7%
Self	1	0.4%	2	0.9%
Community	83		80	
Private (Family)	50	60.2%	49	61.3%
State Guardian	33	39.8%	31	38.8%

Among the 80 former Woodbridge residents living in community settings at the start of Year 2, private guardians also were more common with 61.3% of the residents with community placements having family guardians, predominantly parents or siblings. A total of 38.8% of community residents had state guardians.⁹

There were four guardianship changes during Year 2 for the DC residents. There were no guardianship changes during Year 2 for any of the community residents.

Moves to Different Settings

A move or transfer consisted of a change that followed the residential placement on January 8, 2016, the first day of the report period. Changes included movement from a developmental center into the community or when residents were transferred from one community 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 SNF as a per-

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

⁹ Of the four individuals in the community who passed away during Year 2, all four had state appointed guardians at the time of death.

manent 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.¹⁰
- 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).¹¹

Based upon this definition and analysis, three or 3.8% of the 80 individuals residing in community placements at the start of the report period experienced residential movements in Year 2. In two cases, one move occurred and in one case, there were two moves. One individual moved from a residence operated by one community agency to one operated by another agency. Two individuals moved from a group home to a skilled nursing facility. One of those individuals moved to another skilled nursing facility, resulting in two moves during Year 2. Of the 212 Woodbridge residents who were placed in other developmental centers, three or 1.4% moved in Year 2. One individual was placed in another developmental center and two moved to the community.

None of the Woodbridge residents placed in the community was admitted to a state psychiatric hospital during the second year of the study.¹²

Community Services

Services for people affected by the closure of Woodbridge 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 Re-

¹⁰ 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.

¹¹ 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 examined the Pre-Admission Screening and Resident Review (PASRR) document for guidance.

¹² Community residents were cross-referenced with the Division of Mental Health and Addiction Services and the Department of Health’s shared state psychiatric hospital database for hospitalizations occurring from January 8, 2016 through January 7, 2017.

newal 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 being served. To examine the staffing at these community placements, a 10% random sample (n=9) was selected.¹⁴ The per capita hours of direct service staffing in these placements was calculated resulting in an average of 77.9 weekly direct staffing hours with a range from 50.4 to 111 hours per person per week.

The number of direct care staffing hours is significantly associated with the number of residents in the placement and the time of day associated with clients being in or out of the home: the more residents in a placement, the higher the number of direct care staffing hours.¹⁵ However, other factors may come into play in determining staffing levels. Two of the placements were managed by the same agency and thus offer the best basis for comparison. One of these placements had 82.5 while the other had 70.7 weekly per capita hours; such differences are based on needs of individuals. 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 residents were present all day and might leave the residence for shopping, lunch or social or recreational activities. In the event that consumers are sick and unable to attend their day programs, staffing is provided; similarly, additional staff is hired on an as needed basis for special activities or to ensure adequate coverage.

Of the 80 residents in community placements, all but seven participated in some type of out-of-home day activity. Day habilitation programs provide training and support for individuals with developmental disabilities to participate in activities based upon their preferences and needs, as

Table 5 Types of day activities

Day Activity	N	%
DDD-Funded Adult Training (various types)	61	76.3
DDD-Funded In-Home Supports	7	8.8
State Plan Funded Medical Day Programs	11	13.8
Senior Care	1	1.3
Total	80	100.0

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 10th individual was selected and the program descriptions for their community facilities reviewed.

¹⁵ Pearson correlation = .779, statistically significant at the .05 level.

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.

Sixty-one individuals participated in a DDD-funded formal adult training program available outside of the residential placement setting. These programs were of two types, depending on the level of support needed.

Eleven 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.¹⁶ One individual was in senior care.

Seven individuals received in-home supports. These individuals were not currently participating in day programs for a variety of reasons including individual preference, retirement, and pending day program placements.

The Community Care Waiver provides transportation between the individual’s residence and the location of the day habilitation service as a component part of habilitation services.¹⁷ 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 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.”¹⁸ 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 Client Information System (CIS). Analysis showed that 72 of 80 individuals or about 90% had an annual medical examination during Year 2. Of the eight individuals who did not receive a routine medical examination, four passed away before their scheduled annual examination date. Among the other four, two had medical examinations that occurred just days before the start of the Year 2 pe-

¹⁶ 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

¹⁷ See

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

¹⁸ See http://www.state.nj.us/humanservices/ool/documents/10_44A_eff_4_18_05.pdf

riod, with the Year 2 examinations occurring two or three weeks after the end of the Year 2 report period, one was transferred to a SNF before an examination could be completed and one had the Year 1 examination the month before the start of the Year 2 report period with the Year 2 examination occurring about four months into the Year 3 report period.

The licensing standards for residents of group homes as set forth in New Jersey's Administrative Code¹⁹ 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) and CIS. 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.

Seventy individuals or 87.5% of the 80 in the community received dental care during Year 2. Ten individuals did not receive annual dental care during the reporting period. Of the ten, two residents received no dental care in Year 2 because they passed away before a dental exam was slated to occur. One individual moved to a SNF during the first quarter of the report period. Seven individuals were overdue for an annual dental examination or experienced issues completing an annual exam. A common concern appears to have been related to 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.

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.²⁰ 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 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.

During Year 2, thirty-six individuals, or 45.0% of the 80 individuals living in the community, had one or more incidents that triggered a 9-1-1 call in compliance with Danielle's Law. Nearly all (99.2%) of the incidents reflected medical issues, while only one was *exclusively* behavioral. The total number of Danielle's Law-coded incidents was 121.

¹⁹ Ibid.

²⁰ See http://www.nj.gov/health/fhs/epilepsy/documents/danielles_Law.pdf

epilepsy/convulsions. It is important to note that Danielle’s Law elevates ER visits as a consequence of mandated 9-1-1 calls.

Of the 80 Woodbridge residents who moved to the community, 21 or 26.25% had one or more hospitalizations for medical conditions during Year 2, with enterocolitis, epilepsy, and pneumonia the most common reasons cited.

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 80 residents living in community placements, 42, or 52.5%, had emergency room visits during Year 2. The number of visits ranged from one to more than seven, with a mean of 2.93 (among those with visits). The most common reason given for the emergency room visit was

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?

Table 6 ER visits during Year 2

# of ER visits	N	Percent
0	38	47.5%
1	19	23.8%
2	8	10.0%
3	4	5.0%
4	2	2.5%
5-6	6	7.5%
7+	3	3.8%
Total	80	100.0%

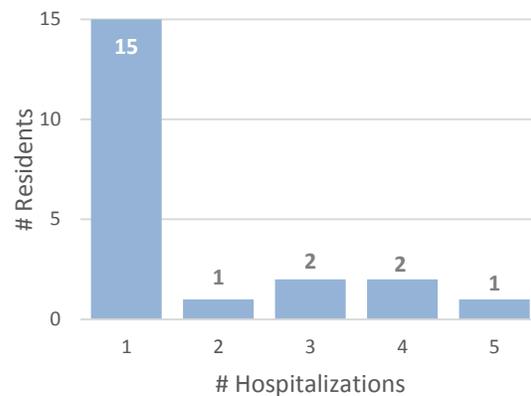


Figure 3 Number of hospitalizations in Year 2

Table 7 Top reasons for hospitalizations

Reason	N
Enterocolitis	4
Epilepsy	4
Pneumonia	4
Urinary Tract Infection	3
Sepsis	3

New Jersey Comprehensive Assessment Tool

The tool used to assess individuals' functioning was developed by the Developmental Disabilities Planning Institute (DDPI), created 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.²¹

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 the Year 2 score and compares scores for individuals placed in the community and those placed in other DCs. Data were available for 70 of the 73 community residents and all of the 203 DC residents. Within group comparisons are made between Years 1 and 2, including determination of statistically significant differences in these scores between those who were in DCs in both Years 1 and 2 (n=197) and those who were in community placements in both years (n=69).

The cognition scale consisted of 20 items.²² 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 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 0.91 and for the DC residents was 1.02. A statistical analysis shows that these differences were not statistically significant.²³

Comparisons between Year 1 and Year 2 cognition scores for individuals in the community showed no significant differences. The DC residents showed a significant decline in cognition scale scores in Year 2.

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

²¹ 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.

²² The original NJCAT includes 21 items. One of the items was omitted for this analysis due to missing values for more than 71% of the Woodbridge residents.

²³ Note that all tests of statistical significance are t-tests of difference of means for independent samples where equal variances are not assumed.

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.

Average scale scores for the community residents was 7.68 and for the DC residents was 10.72. Due to the wide dispersion and skew of the scores, the average is not a valid measure of the central tendency. The distributions are reflected in the graphs in Figure 4 and show that the majority of individuals residing in both the community and the developmental centers had scores of zero.

Given the substantial skew in basic self-care scores, the analysis utilizes a dichotomous variable that captures whether or not the self-care scores reflect a substantial limitation. According to NJCAT documentation, summary scores of less than 34 on basic self-care indicate a substantial limitation while scores above that threshold indicate no substantial limitation. Data show that almost all of the individuals have a substantial limitation with negligible differences between DCs and the community.

Meaningful comparisons of Years 1 and 2 for community residents could not be made given the lack of variability in scores. Sixty-eight of the 69 individuals residing in the community during both years had a substantial self-care limitation during Year 1; all 69 had a substantial limitation during Year 2.

The DC residents showed a significant change in self-care limitation from Year 1 to Year 2. Twelve individuals did not have a substantial self-care limitation in Year 1; only five had no substantial self-care limitation in Year 2. A large majority in both years had substantial self-care

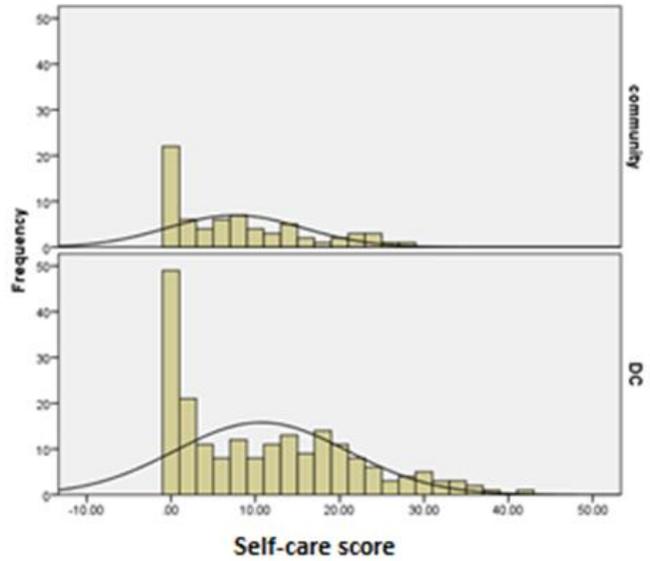


Figure 4 Basic self-care scores of community and DC residents, Year 2

Table 8 Limitation in basic self-care by type of residence during Year 2

Limitation	Community	DC
No substantial limitation	0.0%	2.5%
Substantial limitation	100.0%	97.5%

limitations. Statistical significance, however, cannot be reliably determined due to small sample sizes, in particular the small number of residents without substantial limitations.²⁴

The question is as follows: *“Does (name) walk independently without difficulty, without using a corrective device, and/or without receiving assistance.”* Analysis of Year 2 data shows 18.6% of the community residents and 24.1% of the DC residents were able to walk independently in Year 2. These differences were not statistically significant between community and DC cohorts. Comparisons of Years 1 and 2 suggest very slight differences among the DC residents. Statistical significance testing was not feasible given small sample sizes.

Consumer Interviews

Consumers were interviewed in order to determine their satisfaction with residential placements and whether they would prefer to live in a developmental center. In order to determine who could be interviewed, the researchers analyzed information from the most recent NJCAT to determine the likelihood that former residents could make a comparison and were able to recollect past experiences. Three items were utilized for this purpose: whether former residents knew the differences 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.

Many residents had significant cognitive impairment and could not be interviewed. Four community residents were determined eligible to be interviewed based on the NJCAT information. One of the four was unable to participate; results are based upon in-depth interviews with three community residents. The same DHS staff person interviewed each of these residents, either at the consumer’s residence (N=1) or day program (N=2). 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, including Woodbridge or another group home.

Among the three community residents who could be interviewed about their housing preferences, all preferred living in the community to living at Woodbridge. Two of the three were happy with their current placements; one responded, “I like it here. There is peace and quiet.” The other said his current placement was “Great for me.” The third respondent likes the staff and other residents where she lives but reported that she would like to move. When asked why, she replied “I just want to.”

²⁴ The Chi Square statistic is the appropriate test of statistical significance. It requires a minimum of 5 expected “cases” or individuals in each cell of a 2 by 2 table. In this case, at least one cell, did not meet the test criterion.

Family Contacts

Information about contacts residents have with family was obtained from the Alternate Living Arrangement (ALA) document completed by case managers each quarter. Case managers indicated both the type and frequency of family contact for each resident. The results show that 8 of the 80 placed in the community had no family; for two individuals, it was indicated that there was family, but contact information was missing.

Of the remaining 70 with family and ALA information regarding the frequency of contact, 43 had at least annual contact and 27 had no contact during the annual reporting period. Of the 43 with annual contact, 15 had at least weekly contact; 14 had at least monthly contact; 14 had contact at least

once during the year.²⁵ ALAs were not available for two individuals. One individual passed away in the first quarter of the report period and the other moved permanently to a Skilled Nursing Facility during the first quarter.

Seventy-six of the 78 community residents for whom ALAs were available or 97.4% had access to peers, primarily on a daily basis.

Year 2 Family/Guardian Survey: Community Residents

The study also incorporated the perspectives of private guardians about the Woodbridge cohort's quality of life in the current residence. A survey²⁶ was mailed to the family/guardians of everyone (n=48) who had been placed in the community, had private guardians (i.e., family members, friends, or advocates), and were alive at the time the survey was conducted.²⁷

²⁵ The ALA form documents family contact by either the month or quarter. The ALA data were available for 78 of the 80 residents placed in the community.

²⁶ See Appendix. Items were based upon surveys conducted of previous institutional closures in New Jersey.

²⁷ One individual who was in a DC at the start of Year 2 moved to the community at the time surveys were mailed out. Two individuals who lived in the community and had private guardians were not included in the survey because the individual passed away by the time surveys were mailed.

Table 9 Family involvement among community residents

Family involvement	N	%
Family involved	70	87.5%
No family	8	10.0%
Family, no ALA information	2	2.5%

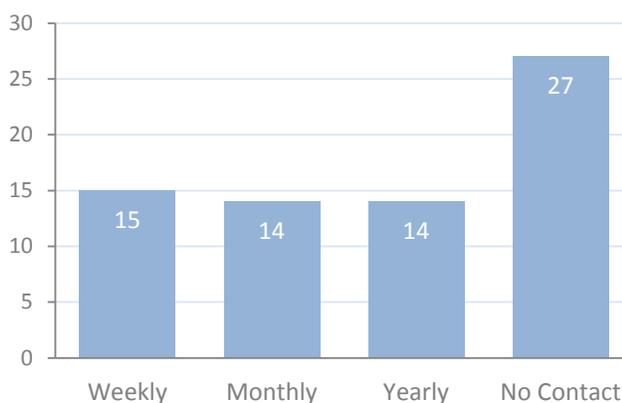


Figure 5 Frequency of family contact (N=70)

Family/guardians who did not respond to the initial mailing received a postcard reminder followed by up to three phone calls.

As of January 1, 2017, family/guardians of 36 former Woodbridge residents living in the community had responded to the survey, a response rate of 75.0%.²⁸ Thirty-five respondents (97.2%) were related to the former Woodbridge resident, while one was a non-related private guardian (2.8%). Relatives were primarily either siblings (55.6%) or parents (38.9%). Other family members included an aunt or uncle and ex-sister-in-law (5.6% combined).²⁹

Most (85.7%) of the respondents (n=30) had visited former Woodbridge residents in their community placements.³⁰ Only one respondent had no contact with the individual placed. Five respondents contacted staff at the residence. Five respondents had contact with residents by phone or email. The totals summed to more than 36, because respondents could have multiple methods of contact. For example, three individuals both visited and had contact via phone or email. Of the five respondents who contacted staff, one also visited the residence. There was one respondent 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. When there was more than one consumer per household, a respondent received a separate survey for each. 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.

²⁸ Of the twelve that have yet to respond, three 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. Three family/guardians of three individuals were reached by phone and confirmed that they had the survey but did not complete the survey during the subsequent month. Family/guardians of the other six individuals could not be reached.

²⁹ Changes in guardianship relationships from the first year's report may reflect differences in who responded to the survey.

³⁰ One respondent left the contact question blank so the percentage is calculated using 35 of the total respondents who answered the question.

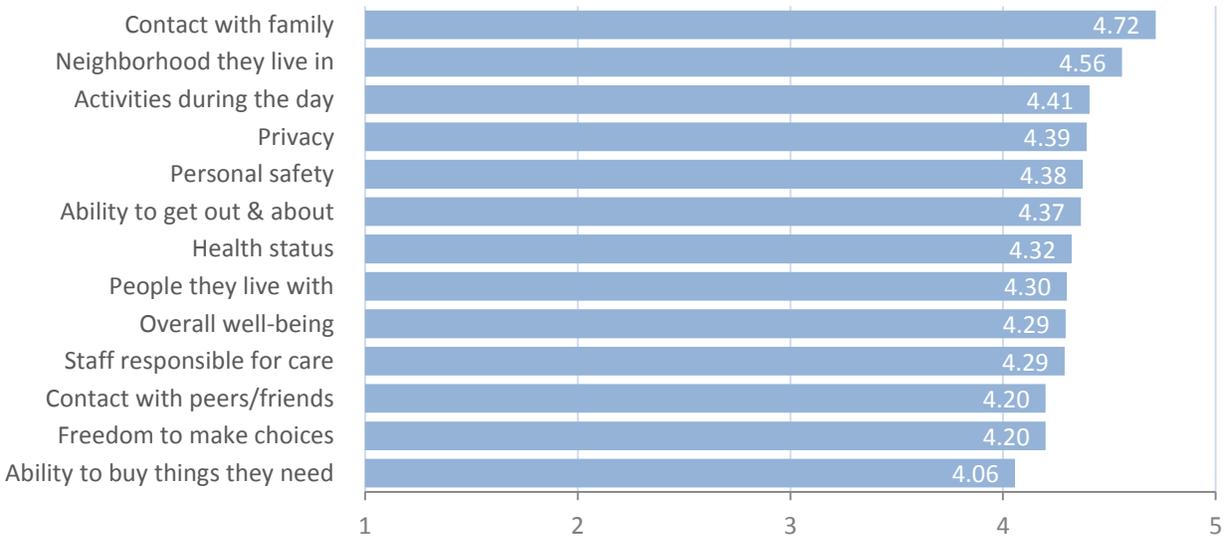


Figure 6 Family guardian perceptions of consumer's current living situation

Average scores for each of the 13 items exceeds a 4 with most items falling between 4 and 5 (indicative of being between “somewhat happy” to “very happy”).³¹

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 with programming and services as shown in figure 7 was evident in the item averages, which ranged from a low of 4.26 to a high of 4.71, where a “5” indicates the

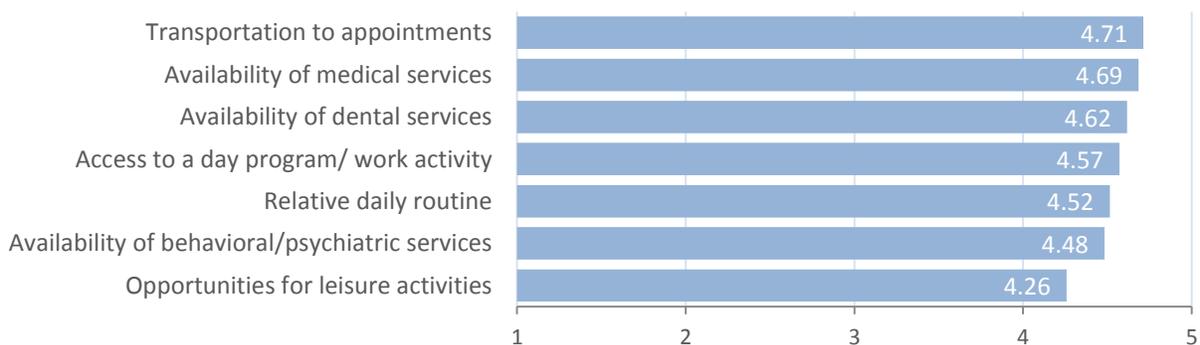


Figure 7 Average ratings of programming and services (higher scores indicate greater satisfaction)

³¹ The legislation specifically mentions personal safety and health status, both of which are rated over 4.0.

respondent is “very satisfied.” The rating for average satisfaction with transportation to appointments at 4.71 was the highest for any of the community programming ratings.

Year 2 Family/Guardian Survey: Community and DC Comparisons

A comparison was made between the perceptions of overall quality of life of private guardians of the Woodbridge residents in community placements to the private guardians of individuals from Woodbridge who were transferred to other developmental centers. In order to make this comparison, surveys were sent to family/guardians of 152 former residents with contact information.³² Family/guardians who did not respond to the initial mailing received a postcard reminder followed by up to three phone calls. As of January 2, 2018 surveys had been received from 114 family/guardians. These included four residents with two family respondents each; one survey for each consumer was chosen at random, leaving 110 surveys and a response rate of 72.4%. All of the respondents were family members, primarily siblings (60.9%) or parents (30.0%); 9.1% of the respondents were aunts/uncles and other family members.

Asked to rate how their relative is doing overall. 28 of 36 (77.8%) guardians of community residents and 92 (84.4%) of 110 guardians of other developmental center residents reported their relative was doing “Excellent/Good”. Six (16.7%)

guardians of community residents and 10 (9.2%) guardians of other developmental centers rated their relative as doing “Fair/Poor.” Two (5.6%) guardians of community residents and eight (6.4%) guardians of residents in other developmental centers did not answer the question or responded “don’t know.”

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. The results showed that in virtually all domains average ratings of quality of life and program satisfaction were slightly higher for community residents. However, with one exception, none of the results were statistically significant. The one domain in which there were differences was staff turnover: Family/guardians of community residents were significantly more likely to feel worried about staff turnover.

Table 10 Guardian perception of relative's well-being

How relative is doing overall	Community (n=36)	DC (n=110)
Excellent/Good	77.8%	84.4%
Fair/Poor	16.7%	9.2%
Don't know/Missing	5.6%	6.4%

³² Family/guardians of twelve former residents with private guardians were not surveyed. Of these twelve, five residents passed away by the time surveys were mailed out, two guardians passed away by the time the survey was sent out, two opted out of the survey, two moved to the community by the time the survey was mailed out, and one guardian’s address was undeliverable and multiple attempts to contact the guardian by phone were unsuccessful.

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 (38.9%); the least frequent change was in roommates (2.8%). Guardians of developmental center residents also reported that the most frequent change was in staff caring for the relative (22.7%) and the least frequent change was in roommates (12.7%).

Table 11 Changes to individual's situation over the past year

Types of changes	Community (n=36)		DC (n=110)	
	N	%	N	%
Moved to a different residence	2	5.6%	17	15.5%
Has a different roommate	1	2.8%	14	12.7%
Has different staff caring for him/her	14	38.9%	25	22.7%
Attends a different day program	3	8.3%	---	---

Family/Guardian Survey: Year 1 and Year 2 Comparisons

The results from surveys of family guardians who completed a survey for both the first and the second report periods were compared. There were 66 family members of individuals living in DCs and 22 from the community that responded to the survey both years of the study. Because of these small sample sizes, statistical significance cannot be determined. As such, the following

Table 12 Changes in average family guardian happiness across several items after Year 2.

Community & Social Interaction	Community (n=22)				DC (n=66)			
	Year 1 Mean	Year 2 Mean	Difference	N	Year 1 Mean	Year 2 Mean	Difference	N
Activities during the day	4.50	4.67	0.17	18	4.38	4.31	-0.06	48
Ability to buy things they need	4.25	4.38	0.13	8	3.87	4.13	0.26	23
Health Status	4.57	4.67	0.10	21	4.23	4.38	0.15	60
Contact with family	4.94	4.94	0.00	18	4.59	4.52	-0.07	56
Neighborhood they live in	4.90	4.85	-0.05	20	4.70	4.45	-0.26	47
Freedom to make choices	4.64	4.55	-0.09	11	4.00	4.22	0.22	18
Personal Safety	4.68	4.58	-0.11	19	4.34	4.38	0.03	58
Ability to get out & about	4.93	4.80	-0.13	15	4.36	4.45	0.10	43
Overall well-being	4.81	4.62	-0.19	21	4.33	4.55	0.22	60
Privacy	4.82	4.59	-0.24	17	4.42	4.47	0.05	38
People they live with	4.76	4.41	-0.35	17	4.46	4.38	-0.08	48
Contact with peers/friends	4.79	4.43	-0.36	14	4.30	4.27	-0.03	30
Staff responsible for care	4.75	4.35	-0.40	20	4.63	4.73	0.10	62

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

results are purely descriptive. As noted throughout, even in situations where satisfaction has decreased, the average scores are still, at minimum, in the positive categories, primarily ranging from “happy” to “very happy.”

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 three items more highly in Year 2 than Year 1. These items were the activities during the day, ability to buy things they need, and health status. Contact with family remained the same from Year 1 to Year 2. The remaining ratings decreased one year later. Despite these numeric decreases, all ratings fell between somewhat happy and very happy.

DC guardians rated eight of the 13 items higher in Year 2 than Year 1. The most improvement in happiness was reported for the consumers’ ability to buy things, freedom to make choices, and overall well-being. The ability to buy things and health status improved among family/guardians of consumers in both the community and DCs. Conversely, perceived happiness with the neighborhood where consumers lived, the people they live with and contact with peer and friends declined in both placement settings.

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. For both the community and the DC, availability of medical services showed the largest increase in average ratings. All averages for Year 2 across all aspects

Table 13 Comparison of average family guardian ratings of satisfaction with aspects of current living arrangement, Year 1 and Year 2.

	Community (n=22)				DC (n=66)			
	Year 1 Mean	Year 2 Mean	Difference	N	Year 1 Mean	Year 2 Mean	Difference	N
Availability of medical services	4.64	4.73	0.09	22	4.58	4.73	0.15	60
Availability of behavioral or psychiatric services	4.53	4.59	0.06	17	4.45	4.52	0.07	42
Daily routine	4.70	4.70	0.00	20	4.58	4.67	0.09	45
Transportation to appointments	4.82	4.82	0.00	22	4.60	4.58	-0.02	50
Availability of dental services	4.59	4.55	-0.05	22	4.58	4.68	0.11	57
Opportunities for leisure activities	4.74	4.68	-0.05	19	4.39	4.51	0.12	41
Access to day program/work activity	4.82	4.55	-0.27	22	4.44	4.47	0.03	36

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

were rated between “somewhat satisfied” and “very satisfied” by both the community and DC guardians. Average ratings for Year 2 are compared to Year 1. Community guardians rated access to day program/work activity, opportunities for leisure activities and availability of dental services lower the second year than the first year. The DC guardians rated all of the aspects higher the second year, except for transportation to appointments which only decreased slightly.

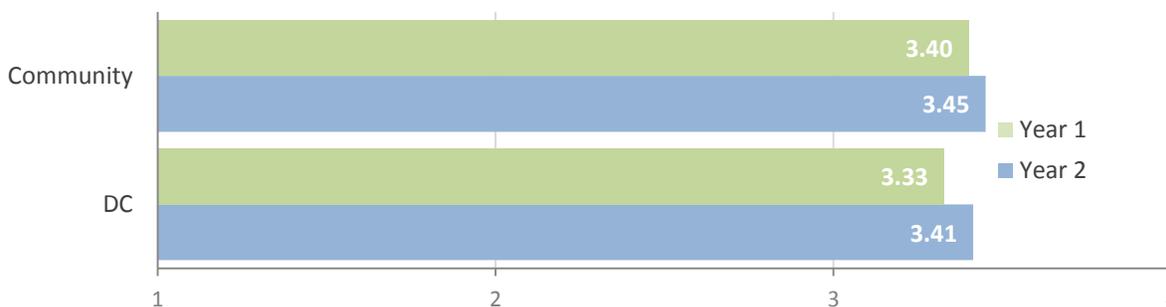


Figure 8 Average community (n=20) and DC guardian (n=58) overall ratings of current living situation by reporting year

Community and DC guardians rated how their relatives were doing in their current living arrangements overall. Ratings were assigned scores from 1 (poor) to 4 (excellent). “Those who responded with “Don’t know” were excluded. The average rating for both the community and DC guardians were between “Good” and “Excellent”. Additionally, both ratings increased after the first year, the community average by 0.05 points and the DC average by 0.08.

Health Status

The study also examined health status outcomes such as the need for medical and behavioral health supports and mortality using the NJCAT tool. The measure of the need for medical supports considers three levels of medical need.³³ As shown Figure 9, 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.³⁴ Within both community and DC residents, there were slight differences in medical supports scores in Year 2 from Year 1. The category with the largest change among community residents was specialized on-site nursing which had a 4.4 percentage point increase. The category among DC residents with the largest change was specialized on-site nursing with a 6.1 percentage point decrease.

³³ 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.

³⁴ Per analyses using Pearson’s chi-square.

The Behavioral Supports Level has scores ranging from 1 to 4, with higher scores associated with behaviors requiring more intensive support and environmental modifications.³⁵

A comparison of data for community and DC residents show that most community residents needed formal behavioral health supports while approximately equal percentages of DC residents needed either no on-site supports or formal supports. Decisions regarding residential placements were made by the residents' guardians. Among those who selected to live in the community, greater behavioral health supports were required than among those who moved to a developmental center. These differences are statistically significant.³⁶

Within both community and DC residents, there were slight differences in behavioral supports scores in Year 2 from Year 1. Among community residents, the category with the largest change was formal supports which increased by 8.7 percentage points. Among DC residents, the category with the largest change was formal supports which decreased by 3.1 percentage points.

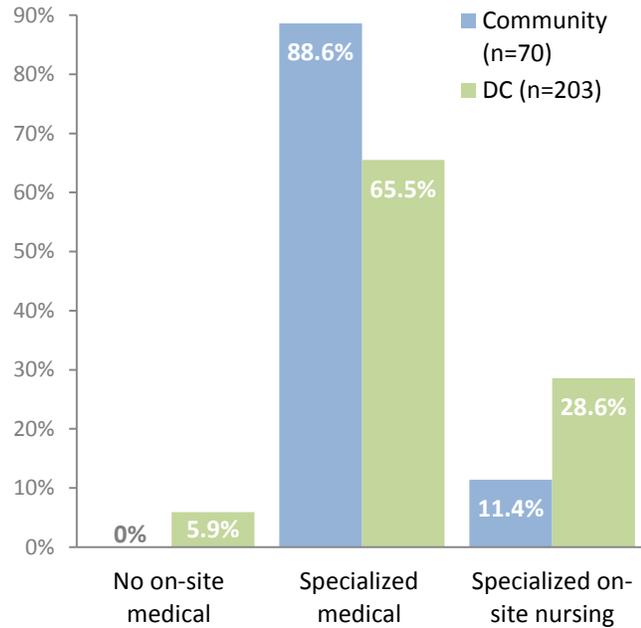


Figure 9 Medical assistance by residential placement type, Year 2

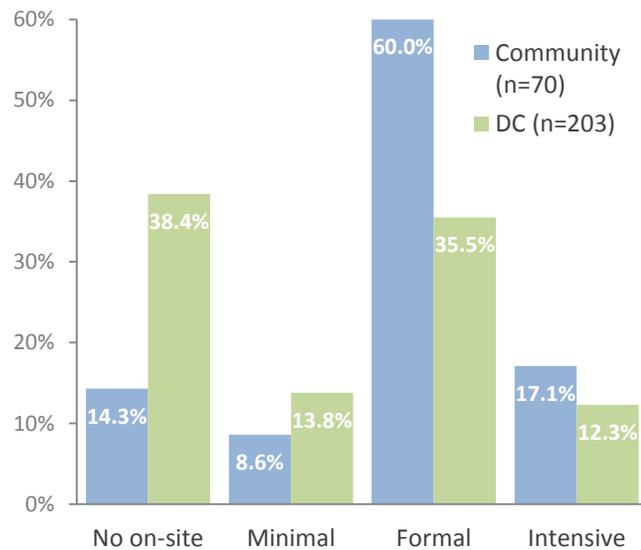


Figure 10 Need for behavioral supports by residential placement type

³⁵ Lerman, et al., op. cit., 188-190.

³⁶ Per analyses (using Pearson's chi-square).

Mortality

Among the 80 individuals living in the community at the start of the report period, five (6.3%) passed away in Year 2.³⁷ Of these five, two were residing in SNFs at the time of death, including one who was in and out of hospitals and SNFs throughout the second year. Six (2.8%) of the 212 individuals who were residing in other developmental centers passed away.³⁸ All deaths during Year 2 were due to natural causes including myocardial infarction, renal failure, respiratory failure, and septic shock.

Unusual Incidents

The Department of Human Services' Unusual Incident Reporting and Management System (UIRMS) 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), or criminal activity. 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. The documentation of law enforcement involvement 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 data yielded one unsubstantiated allegation of neglect. Contact with police show only noise complaints regarding the household and claims of neglect were unsubstantiated. There was no evidence of criminal charges related to any incident occurring during the Year 2 report period.

This concludes the Woodbridge DC closure evaluation for the second annual report (covering the second year post-closure). The third annual report out of five will cover the Year 3 period from January 8, 2017 through January 7, 2018.

³⁷ Both of the individuals who passed away in SNFs were residing in community placements at the start of the report period.

³⁸ One consumer who passed away in the DC was receiving hospice care.

Appendix A: Family Guardian Survey



Family and Guardian Survey - Woodbridge Developmental Center Residents in Community Placements - Year 2

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 Woodbridge 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 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 Woodbridge 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 should have been contacted last year for the first post-Woodbridge survey. This is the second of five annual surveys. Even if you did not receive the first survey, you can still complete this one. 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. 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

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



Family and Guardian Survey - Woodbridge Developmental Center Residents in Community Placements - Year 2

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 Woodbridge 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 Woodbridge Developmental Center? I am: (Select ONE)

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

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

5. 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	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The staff responsible for their care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The activities they have during the day	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Their ability to get out and get around	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The neighborhood they live in	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Their personal safety	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The contact they have with you or other family members	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The contact that they have with peers and friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Their freedom to make choices	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Their ability to buy things they need	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Their privacy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Their health status	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Their overall well-being	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

6. 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	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Preparation of staff to handle behavioral or medical problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Staff turnover	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Risk of abuse or neglect	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

7. 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	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Opportunities for leisure activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access to either a day program or work activity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transportation to appointments or programs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Availability of medical services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Availability of behavioral or psychiatric services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Availability of dental services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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

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

9. 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.

10. 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 WITHIN TWO WEEKS.