*State of New Jersey*

**Department of Human Services**

# Woodbridge Developmental Center Year Three Closure Report

NJ DHS Office of Research, Evaluation & Special Projects

# Table of Contents

## 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 complicate year-to-year comparisons, as some community based individuals have moved to skilled nursing facilities and DC residents to the community.

This report presents data for the third year following the closure of Woodbridge Developmental Center. It addresses the topics mandated in legislation focusing on persons, settings, services and outcomes. Unless otherwise specified, tables and graphs depict information for Year 3. As feasible and appropriate, contextual comparisons are made between consumers moved into community placements and those residing in developmental centers. Information was obtained

[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.

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.

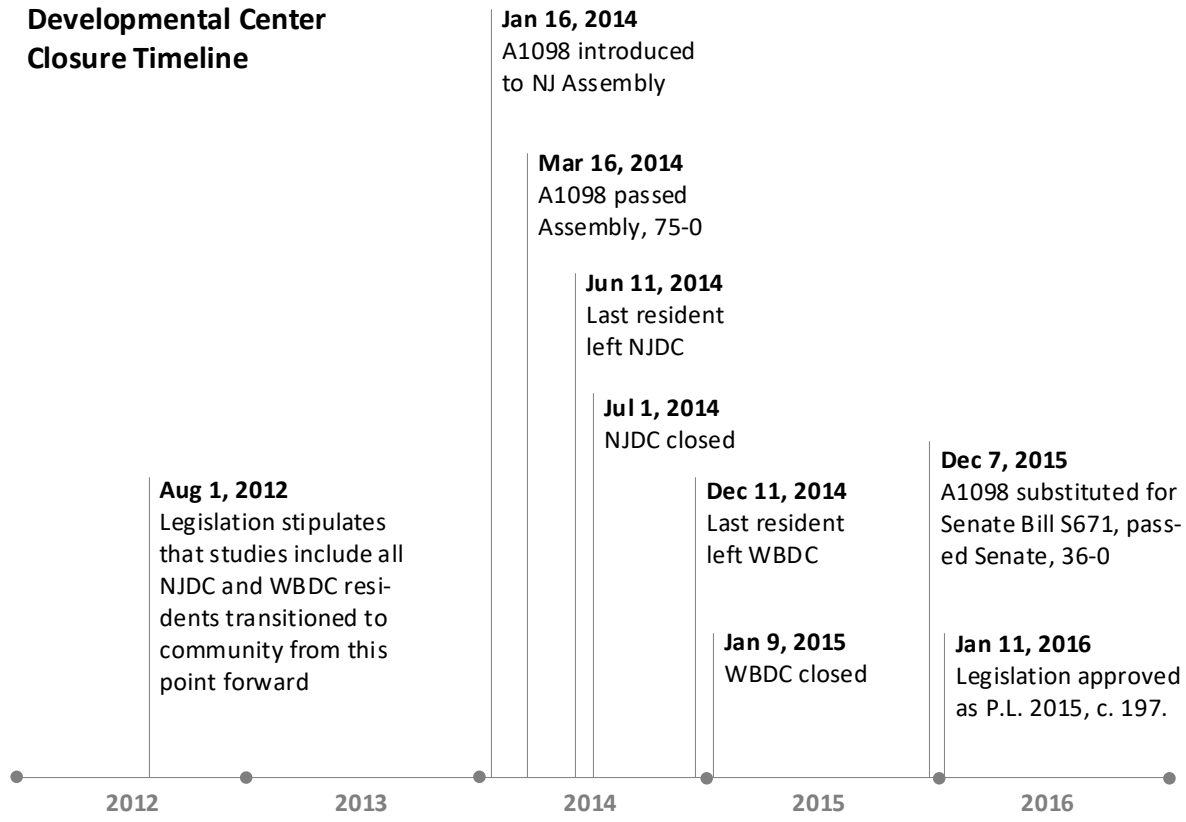


***Figure 1*** Timeline of DC closure

## 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 third report cover the period from January 8, 2017 until January 7, 2018. At the start of that time period, there were 284 members remaining in the cohort. Forty-nine individuals are not part of this report. Between August 1, 2012 and January 7, 2016, ten

***Table 1*** Cohort attrition

| Cohort Attrition | Year 1 | Year 2 | Year 3 |
|---|---|---|---|
| Individuals at the start of the report period | 333 | 295 | 284 |
| Pre-placement deaths | 10 | -- | -- |
| Deaths | 26 | 11 | 6 |
| Discharges | 2 | -- | -- |

individuals passed away prior to moving from Woodbridge. Following placement, between 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 and nothing is known of their status. Eleven passed away during year 2 of the report, January 8, 2016 to January 7, 2017.

## Residential Settings

At the start of the report period, there were 284 former Woodbridge Developmental Center residents. A total of 204 individuals or 71.8% of the 284 former Woodbridge Developmental Center residents were residing in other develop-mental centers.[6] Of the remaining 80 residents, 77 were living in the community. Three residents were in Skilled Nursing Facilities (SNF). This report focuses on the 204 individuals residing in developmental centers and the 77 persons living in the community.

Of the 204 individuals from Woodbridge who were living in Developmental Centers at the start of the report period, 47.1% resided in either Woodbine or Vineland. An additional 20.6% resided in New Lisbon and about 17.2% and 15.2% were living in Green Brook and Hunterdon, respectively.

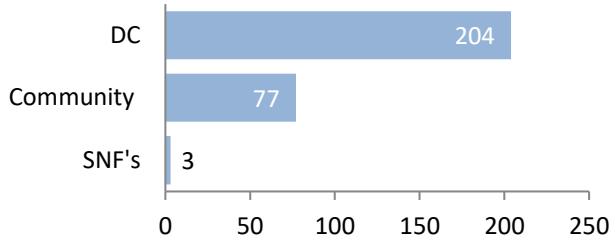


***Figure 2*** Placements from Woodbridge as of 1/8/2017 by type

***Table 2*** DC residents at start of report period by placement

| Developmental Center | N | % |
|---|---|---|
| Woodbine | 52 | 25.5% |
| Vineland | 48 | 21.6% |
| New Lisbon | 42 | 20.6% |
| Green Brook | 34 | 17.2% |
| Hunterdon | 31 | 15.2% |
| Total | 204 | 100.0% |

***Table 3*** Characteristics of Woodbridge Residents on January 8, 2017 (n=284)

| | |
|---|---|
| Gender | |
| Male | 57.4% |
| Female | 42.6% |
| Age Group | |
| 22 - 44 years | 5.6% |
| 45 - 54 years | 20.8% |
| 55 - 64 years | 50.7% |
| 65+ years | 22.9% |

## Persons

The 284 former WBDC residents who were cohort members in January 2017, were more likely to be male (57.4%) and between 55 and 64 years old (50.7%). The

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

mean age of the population was 58.3 years.

Placement decisions were approved by the residents' guardians. Of the 204 former residents of Woodbridge who were living in other developmental centers at the start of the third year of the study, 159 or 77.9% had private guardians, primarily parents[7] and siblings, but also including aunts/uncles, cousins, and other family members. Less than one-fourth (43 or 21.1%) had state guardians; two consumers were their own guardian.

Among the 77 former Woodbridge residents living in community settings at the start of Year 3, private guardians also were more common with 63.6% of the residents with community placements having family guardians, predominantly parents or siblings. A total of 33.8% of community residents had state guardians and two were their own guardian.[8]

There were two guardianship changes from Year 2 to Year 3 for the DC residents. There were three guardianship changes for the community residents.

***Table 4*** Guardians of DC and community residents by study year

| Guardian Type by Placement | Year 1 | | Year 2 | | Year 3 | |
|---|---|---|---|---|---|---|
| | N | % | N | % | N | % |
| Developmental Center | 236 | | 212 | | 204 | |
| Private (Family) | 179 | 75.8 | 164 | 77.4 | 159 | 77.9 |
| State Guardian | 56 | 23.7 | 46 | 21.7 | 43 | 21.1 |
| Self | 1 | 0.4 | 2 | 0.9 | 2 | 1.0 |
| Community | 83 | | 80 | | 77 | |
| Private (Family) | 50 | 60.2 | 49 | 61.3 | 49 | 63.6 |
| State Guardian | 33 | 39.8 | 31 | 38.8 | 26 | 33.8 |
| Self | -- | | -- | | 2 | 2.6 |

## 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 January 8, 2017 through January 7, 2018. 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 a community residential placement into a SNF as a permanent placement, related either to terminal illness or a chronic medical condition requiring nursing care.

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

[8] Of the three individuals in the community who passed away during Year 3, all three had private guardians at the time of death.

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.[9]
- 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).[10]

Based upon this definition and analysis, three or 3.9% of the 77 individuals residing in community placements at the start of the report period experienced residential movements in Year 3. In all cases, only one move occurred. In two cases, individuals moved from a community placement to a skilled nursing facility and in one instance, an individual moved from a community placement to another community placement managed by a different provider. Of the 204 Woodbridge residents who were placed in other developmental centers, six moved in Year 3. Five individuals were placed in another developmental center and one moved to the community.

None of the Woodbridge residents placed in the community was admitted to a state psychiatric hospital during the third year of the study.[11]

## 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 Renewal application was approved in March 2017 and added several new services and habilitative therapies as available options.[12]

[9] 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.

[10] 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.

[11] 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, 2017 through January 7, 2018.

[12] 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,

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=8) was selected.[13] The per capita hours of direct service staffing in these placements was calculated and an average of 72.7 weekly direct staffing hours with a range from 50.5 to 97.0 hours per person per week was found.

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 and out of the home; the more residents in a placement, the higher the number of direct care staffing hours.[14] 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 97.0 weekly per capita hours while the other had 77.0; such differences are based on needs of individuals. Most programs planned for minimal staff during weekday daytime 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 77 residents in community placements, all but five 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 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.

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 Comprehensive Medicaid Waiver, and was re-named the Community Care Program.

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

[14] Pearson correlation = .608, statistically significant at the .05 level.

Sixty-two 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.

***Table 5*** Types of day activities

| Day Activity | N | % |
|---|---|---|
| DDD-Funded Adult Training (various types) | 62 | 80.5 |
| State Plan Funded Medical Day Programs | 9 | 11.7 |
| Senior Care | 1 | 1.3 |
| Retired | 1 | 1.3 |
| None available | 4 | 5.2 |
| Total | 77 | 100.0 |

Nine individuals participated in State Plan Medicaid-funded medical day programs.[15] One individual was in senior care.

Five individuals received in-home supports. These individuals were not currently participating in day programs for a variety of reasons including individual preference and retirement.[16]

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.[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 electronic records, group home staff and support coordinators. Analysis showed that 72 of 77 individuals or about 93.5% had an annual medical examination during Year 3. Of the five individuals who did not

[15] See https://www.state.nj.us/humanservices/doas/services/adc/
[16] One individual later changed their mind and began attending a day program during year 4.
[17] 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
[18] See http://www.state.nj.us/humanservices/ool/documents/10_44A_eff_4_18_05.pdf

receive a routine medical examination, two passed away before their scheduled annual examination date. Among the other three, two had medical examinations that occurred just days before the start of the Year 3 period, with the Year 4 examinations occurring about two weeks after the end of the Year 3 report period, and one was transferred to a SNF before an examination could be completed.

The licensing standards for residents of group homes as set forth in New Jersey's Administrative Code[19] 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), residential staff, and DDD's electronic records. 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-two individuals or 93.5% of the 77 in the community received dental care during Year 3. Five individuals did not receive annual dental care during the reporting period. One individual did not have an annual dental exam because the individual was in a hospital at the time of the scheduled dental exam and was close to the end of the report period. Another individual attempted multiple times to complete an annual dental but for various reasons, the exam was not completed until the following year. Due to health conditions, another individual had not completed an annual dental. The fourth individual did not complete an exam because they would have needed sedation and the individual was ineligible for sedation due to other health conditions. The fifth individual's guardian opted to have the individual's primary care physician complete the dental exam due to various reasons.

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.

[19] Ibid.

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

During Year 3, forty-three, or 55.8% of the 77 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 (96.6%) of the incidents reflected medical issues, while five were behavioral. The total number of Danielle's Law-coded incidents was 149.

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 77 residents living in community placements, 47, or 61.0%, had emergency room visits during Year 3. The number of visits ranged from one to more than seven, with a mean of 3.02 (among those with visits). The most common reasons given for the emergency room visit were head, ear or eye laceration, contusion, abrasion or other injury, gastrostomy malfunction and epilepsy, convulsions, or seizures. It is important to note that Danielle's Law elevates ER visits as a consequence of mandated 9-1-1 calls.

Of the 77 Woodbridge residents living in the community, 26 or 33.8% had one or more hospitalizations for medical conditions, with epilepsy or seizures being the most common reasons cited.

***Table 5*** ER visits during Year 3

| # of ER visits | N | Percent |
|---|---|---|
| 0 | 30 | 39.0% |
| 1 | 20 | 26.0% |
| 2 | 7 | 9.1% |
| 3 | 7 | 9.1% |
| 4 | 4 | 5.2% |
| 5-6 | 4 | 5.2% |
| 7+ | 5 | 6.5% |
| Total | 77 | 100.0% |

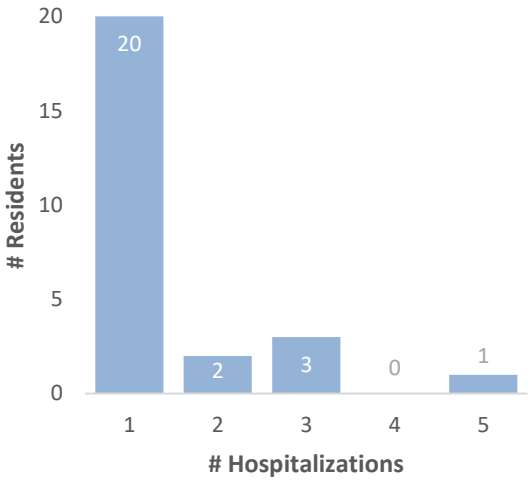


***Figure 3*** Number of hospitalizations in Year 3

***Table 6*** Top reasons for hospitalizations

| Reason | N |
|---|---|
| Epilepsy/seizures | 10 |
| Urinary tract infection | 4 |
| Sepsis | 4 |
| Aspiration pneumonia/other pneumonia | 3 |

## 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 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 for Year 3 and compares scores for individuals placed in the community to those placed in other DCs. Data were available for 69 of the 77 community residents and 187 of the 204 DC residents. Within group comparisons are also made between Years 1 and 3, including determination of statistically significant differences in these scores between those who were in DCs in both Years 1 and 3 (n=181) and those who were in community placements in both years (n=66).

[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.

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 0.88 and for the DC residents was 1.06.

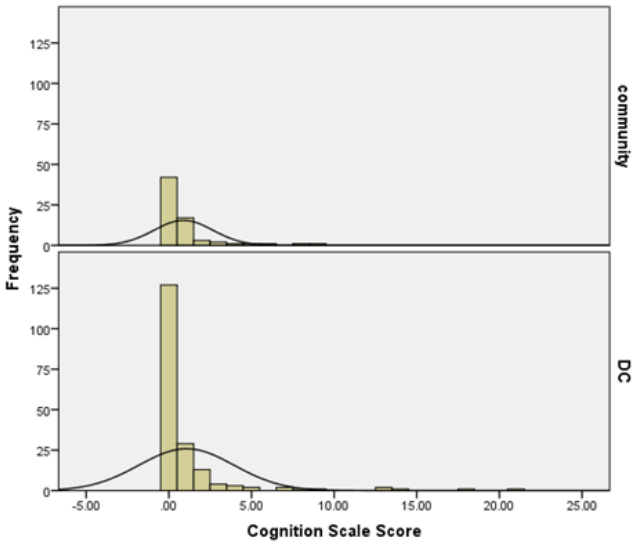


***Figure 4*** Cognition scores of community and DC residents, Year 3

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.

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 8) show that almost all 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.

**Table 7** Percentage with a cognitive limitation by type of residence

| Limitation | Community | DC |
|---|---|---|
| No substantial limitation | 0.0% | 1.1% |
| Substantial limitation | 100.0% | 98.9% |

Comparisons between Year 1 and Year 3 cognition scores for individuals in the community showed no significant differences. The DC residents showed a decline in cognition scale scores in Year 3[22].

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

[22] Statistical significance could not be tested due to the wide dispersion of scores.

hands/face, brushing hair, adjusting water temperature, drying body after bathing, tying shoes (using laces or Velcro), and using tissues to wipe/blow nose. Total scores could range from 0 if individuals were unable to perform any of the tasks to 42 among individuals able to perform all tasks independently.

The average scale score for the community residents was 8.22 and for the DC residents was 11.19.

Due to the wide dispersion and skew of the scores, the average is not a valid measure of the central tendency. The distributions in Figure 5 show that the majority of individuals residing in both the community and the developmental centers had scores of zero.

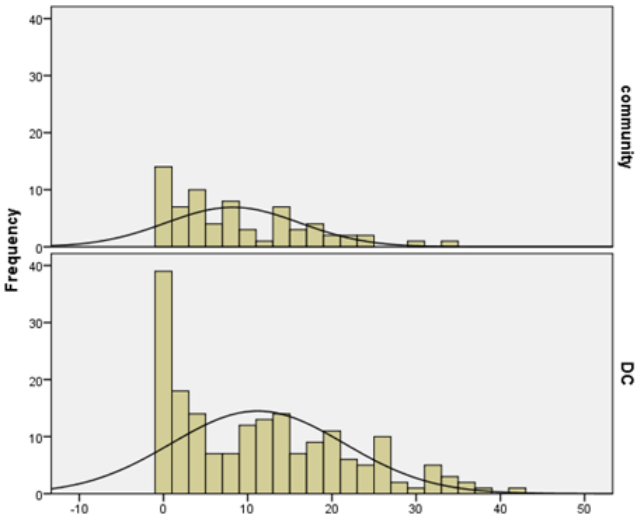


**Figure 5** Basic self-care scores of community and DC residents, Year 3

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.

***Table 8*** Limitation in basic self-care by type of residence

| Limitation | Community | DC |
|---|---|---|
| No substantial limitation | 0.0% | 2.1% |
| Substantial limitation | 100.0% | 97.9% |

Meaningful comparisons of Years 1 and 3 for community residents could not be made due to lack of variability in scores. Sixty-five of the 66 individuals residing in the community during both years had a substantial self-care limitation during Year 1; all 66 had a substantial limitation during year 3.

Meaningful comparisons of Years 1 and 3 self-care limitations for DC residents could not be made due to lack of variability in scores and the small number of residents without substantial limitations. Twelve individuals did not have a substantial self-care limitation in Year 1; only four had no substantial limitation during Year 3. A large majority in both years had substantial self-care limitations.

This question captured mobility: *"Does (name) walk independently without difficulty, without using a corrective device, and/or without receiving assistance."* Analysis of Year 3 data shows 14.5% of the community residents and 23.5% of the DC residents were able to walk independently in Year 3. These differences were not statistically significant between community and DC cohorts. Comparisons of Years 1 and 3 suggest very slight differences among community and DC residents. Statistical testing was not feasible for the community residents given the small sample size. Thirty-seven DC residents were able to walk independently during Year 1 and 44 residents in Year 3. This difference was statistically significant[23].

## 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. Four items were utilized for this purpose: whether former residents were able to remember events that happened a month or more ago, understood the difference between yesterday, today and tomorrow, were able to use a few simple words, signs or picture symbols, and were able to understand a joke or story[24].

Many residents had significant cognitive impairment and could not be interviewed. The three individuals who were eligible for the second interview were also interviewed for Year 3; results are based upon in-depth interviews with the three community residents. Individuals were interviewed 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 DC. One of the three was happy with their current placement; this individual responded, "It's great" and spoke about the meals, day programming and trips they have gone on in the community. The other two individuals both preferred to live in the community but wanted to move to another group home. One individual said they "want to move down the hill" but the reason is unclear, but could possibly be to be closer to family or closer to a former roommate that they miss. When the individual was asked if they like the staff and if they were happy, the individual nodded affirmatively to both. The reason the other individual who wanted to move to another group home was also unclear

[23] Different respondents each year and the question not allowing for nuanced responses are reasons why mobility could be perceived to improve.
[24] The individuals identified using the first year NJCAT scores were interviewed for the second and third year.

but could possibly be because they want to be closer to their mother who they frequently spoke about or to "get away from the clients". This respondent indicated that they like the staff.

## 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 the frequency of family contact for each resident. There was one individual without an ALA. Where data were available, results show that 10 of the 76 placed in the community had no family.

Of the remaining 66 with family and ALA information regarding the frequency of contact, 48 had at least annual contact and 18 had no contact during the annual reporting period. Of the 48 with annual contact, 18 had at least weekly contact; 19 had at least monthly contact; 11 had at least once during the year.[25]

***Table 9*** Family involvement among community residents

| Family involvement | N | % |
|---|---|---|
| Family involved | 66 | 85.7% |
| No family | 10 | 13.0% |
| Missing ALA information | 1 | 1.3% |

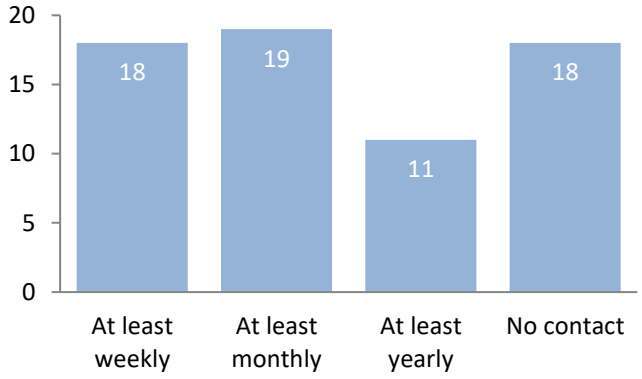


***Figure 6*** Frequency of family contact (N=66)

Seventy-five of the 76 community residents for whom ALAs were available or 98.7% had access to peers, primarily on a daily basis.

## Year 3 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 survey[26] was mailed to the family/guardians of everyone (n=45) who had been placed in the community, still resided in the community at the time of the survey, had private guardians (i.e., family members, friends, or advocates) and did not opt out of the survey in previous years. Family/guardians who did not respond to the initial mailing received a postcard reminder followed by up to three phone calls.

[25] The ALA form documents family contact by either the month or quarter. The ALA data were available for 76 of the 77 residents placed in the community.

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

As of November 15, 2018, 36 family/guardians of 32 former Woodbridge residents living in the community had responded to the survey, a response rate of 71.1%. [27] Thirty-one respondents (96.9%) were related to the former Woodbridge resident, while one was a unrelated private guardian (3.1%). Relatives were primarily either siblings (56.3%) or parents (31.3%). Other family members included an aunt or uncle, counsin and ex-sister-in-law (12.5% combined).[28]

Most (83.9%) of the respondents (n=26) had visited former Woodbridge residents in their community placements.[29] All of the individuals that responded to the question had some form of contact with their loved one. Ten respondents contacted staff at the residence. Seven respondents had contact with residents by phone or email. The totals summed to more than 31, because respondents could have multiple methods of contact. For example, three individuals both visited and had contact via phone or email. Of the ten respondents who contacted staff, three also visited the residence. There were three 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

[27] Where there were more than one respondent for one individual, one survey for each individual was chosen at random.

[28] Changes in guardianship relationships from the previous reports may reflect differences in who responded to the survey.

[29] One respondent left the contact question blank so the percentage is calculated using 31 of the total respondents who answered the question.

follows: "very happy"= 5; "somewhat happy" = 4; "neither happy nor unhappy" = 3; "somewhat unhappy" = 2; and "very unhappy" = 1.

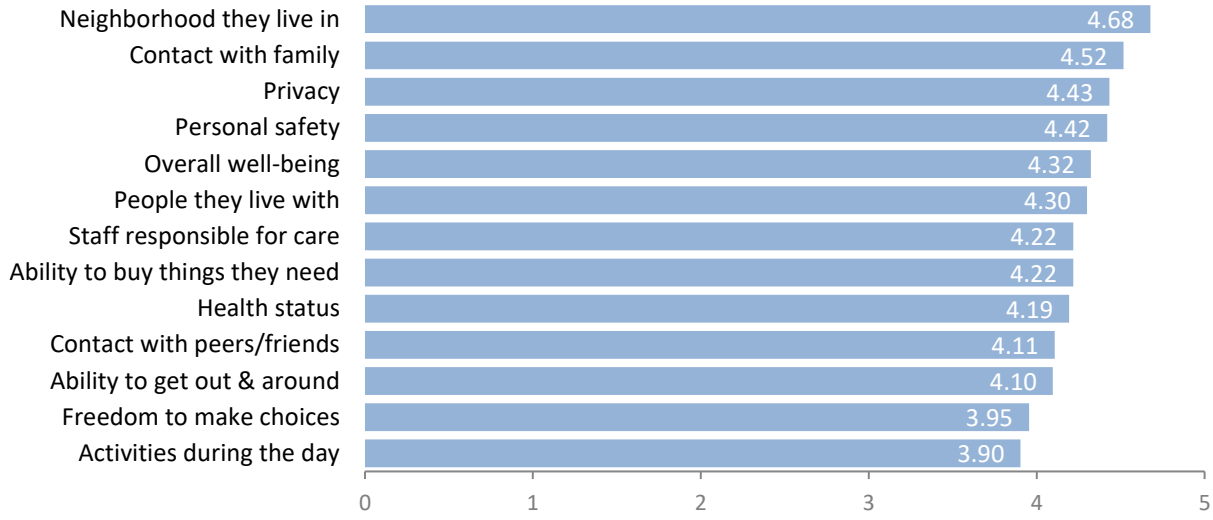


**Figure 7** Family guardian perceptions of consumer's current living situation

Average scores for each of the 13 items fall between 3.90 and 4.68 with the neighborhood they live in the highest for any of the community ratings.[30]

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.

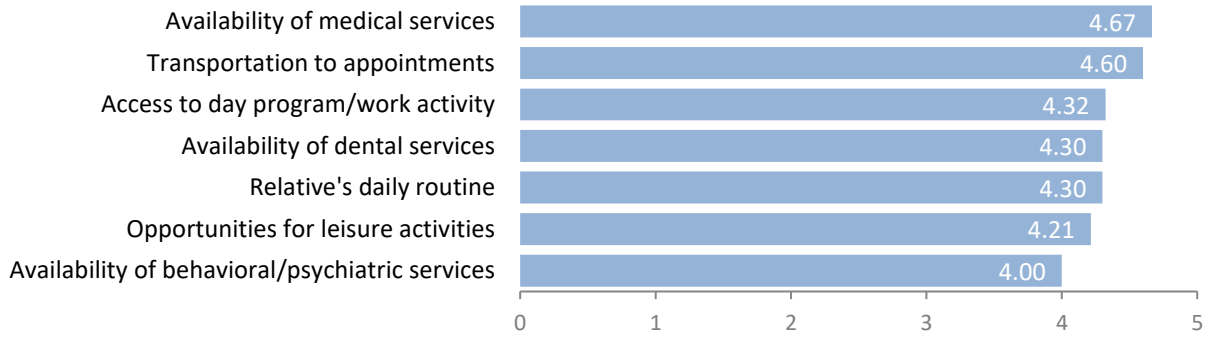


***Figure 8*** Average ratings of programming and services (higher scores indicate greater satisfaction)

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

High reported satisfaction in programming and services as shown in Figure 8 was evident in the item averages, which ranged from a low of 4.00 to a high of 4.67, where a "5" indicates the respondent is "very satisfied." The rating for average satisfaction with availability of medical services at 4.67 was the highest for any of the community programming ratings.

## Year 3 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 141 residents who had been placed in another developmental center, still resided in a developmental center at the time of the survey, had private guardians (i.e., family members, friends, or advocates) and did not opt out 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 November 15, 2018 surveys had been received from 103 family/guardians. These included four residents with two family respondents each; one survey for each individual was chosen at random, leaving 99 respondents and a response rate of 70.2%. All of the respondents were family members, primarily siblings (69.6%) or parents (31.3%); 9.1% of the respondents were aunts/uncles, cousins and other family members.

***Table 10*** Guardian perception of relative's well-being

| **How relative is doing overall** | **Community (n=32)** | **DC (n=99)** |
|---|---|---|
| Excellent/Good | 84.4% | 81.8% |
| Fair/Poor | 12.5% | 9.1% |
| Don't know/Missing | 3.1% | 9.1% |

Asked to rate how their relative is doing overall. 27 of 32 (84.4%) guardians of community residents and 81 of 99 (81.8%) guardians of other developmental center residents reported their relative was doing "Excellent/Good". Four (12.5%) guardians of community residents and nine (9.1%) guardians of other developmental centers rated their relative as doing "Fair/Poor." One (3.1%) guardians of community residents and nine (9.1%) 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. However, with a few exceptions, none of the results were statistically significant. Domains in which family/guardians of former DC residents were statistically significantly happier or more satisfied were the activities they have during the day and availability of behavioral or psychiatric services. Family/Guardians of former community residents were statistically significantly more worried about preparation of staff to handle behavioral or medical problems.

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%); the least frequent change was in roommates (9.4%). Guardians of developmental center residents also reported that the most frequent change was in staff caring for the relative (27.3%) and the least frequent change was move to a different residence (10.1%).

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

| Types of changes | Community (n=32) | | DC (n=99) | |
|---|---|---|---|---|
| | N | % | N | % |
| Moved to a different residence | 4 | 12.5% | 10 | 10.1% |
| Has a different roommate | 3 | 9.4% | 13 | 13.1% |
| Has different staff caring for him/her | 16 | 50.0% | 27 | 27.3% |
| Attends a different day program | 5 | 15.6% | --- | --- |

## Family/Guardian Survey: Year 1 and Year 3 Comparisons

The results from surveys of family guardians who completed a survey for both the first and the third report periods were compared. There were 61 family members of individuals living in DCs and 21 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 minimum, in the positive categories, primarily ranging from "happy" to "very happy." [31]

[31] Exceptions are freedom to make choices and activities during the day.

***Table 12*** Changes in average family guardian happiness across several items after Year 1. Note: Sample sizes vary by item due to variations in item response; the term, "mean" is synonymous with the average score.

| **Community & Social Interaction** | **Year 1 Mean** | **Year 3 Mean** | **Differ-ence** | **N** | **Year 1 Mean** | **Year 3 Mean** | **Difference** | **N** |
|---|---|---|---|---|---|---|---|---|
| Ability to buy things they need | 4.14 | 4.14 | 0.00 | 14 | 4.38 | 4.67 | 0.29 | 21 |
| Neighborhood they live in | 4.95 | 4.67 | -0.29 | 21 | 4.64 | 4.57 | -0.07 | 44 |
| Personal Safety | 4.80 | 4.40 | -0.40 | 20 | 4.43 | 4.58 | 0.15 | 53 |
| Contact with family | 4.85 | 4.45 | -0.40 | 20 | 4.65 | 4.67 | 0.02 | 46 |
| People they live with | 4.84 | 4.42 | -0.42 | 19 | 4.40 | 4.53 | 0.13 | 45 |
| Health status | 4.65 | 4.20 | -0.45 | 20 | 4.32 | 4.47 | 0.15 | 53 |
| Privacy | 4.95 | 4.47 | -0.47 | 19 | 4.44 | 4.53 | 0.09 | 34 |
| Overall well-being | 4.90 | 4.40 | -0.50 | 20 | 4.40 | 4.64 | 0.24 | 55 |
| Staff responsible for care | 4.81 | 4.29 | -0.52 | 21 | 4.69 | 4.73 | 0.04 | 52 |
| Freedom to make choices | 4.50 | 3.93 | -0.57 | 14 | 4.33 | 4.72 | 0.39 | 18 |
| Contact with peers/friends | 4.82 | 4.18 | -0.65 | 17 | 4.33 | 4.33 | 0.00 | 30 |
| Ability to get out & about | 4.90 | 4.25 | -0.65 | 20 | 4.33 | 4.35 | 0.03 | 40 |
| Activities during the day | 4.60 | 3.90 | -0.70 | 20 | 4.42 | 4.51 | 0.09 | 43 |

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 their ability to buy things they need the same in Year 1 and Year 3. The remaining ratings decreased two years later. Despite these numeric decreases, most ratings fell between somewhat happy and very happy. [32]

DC guardians rated eight of the 11 items higher in Year 3 than Year 1. The most improvement in happiness was reported for the consumers' freedom to make choices, ability to buy things they need and overall well-being. Perceived happiness with the neighborhood where consumers lived declined in both placement settings.

[32] The data show that among the small number of community residents with data at both intervals, ratings almost invariably declined. However, for those in a DC during both time periods, ratings were unchanged or increased. The decrease in community ratings may reflect regression towards the mean since higher ratings are most apt to fall.

***Table 13*** Comparison of average family guardian ratings of satisfaction with aspects of current living arrangement, Year 1 and Year 3. Note: Sample sizes vary by item due to variations in item response; the term "mean" is synonymous with the average score.

| | Year 1 Mean | Year 3 Mean | Difference | N | Year 1 Mean | Year 3 Mean | Difference | N |
|---|---|---|---|---|---|---|---|---|
| Availability of medical services | 4.70 | 4.65 | -0.05 | 20 | 4.61 | 4.82 | 0.21 | 56 |
| Transportation to appointments | 4.9 | 4.65 | -0.25 | 20 | 4.60 | 4.67 | 0.07 | 45 |
| Opportunities for leisure activities | 4.74 | 4.47 | -0.26 | 19 | 4.43 | 4.48 | 0.05 | 40 |
| Daily routine | 4.84 | 4.42 | -0.42 | 19 | 4.53 | 4.56 | 0.02 | 45 |
| Access to day program/work activity | 4.85 | 4.35 | -0.50 | 20 | 4.31 | 4.42 | 0.11 | 36 |
| Availability of behavioral/psychiatric services | 4.61 | 4.06 | -0.56 | 18 | 4.42 | 4.67 | 0.26 | 43 |
| Availability of dental services | 4.75 | 4.15 | -0.60 | 20 | 4.53 | 4.62 | 0.09 | 53 |

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 3 are compared to Year 1. All averages for Year 3 across all aspects were rated between "somewhat satisfied" and "very satisfied" by both the community and DC guardians. Community guardians rated all programming lower the third year than the first year. The DC guardians rated all of the aspects higher the third year. The largest increases in programming satisfaction of family/guardians of DC residents were availability of behavioral or psychiatric services and availability of medical services.

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. The average ratings for both the community and DC guardians were between "Good" and "Excellent". Additionally, DC ratings increased after the first year by 0.13 and the community decreased by 0.58.

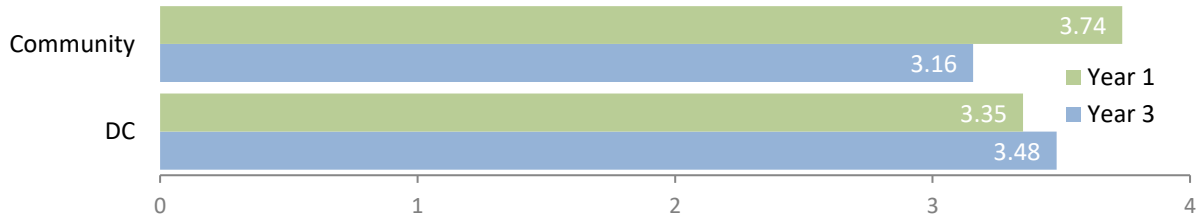


***Figure 9*** Average community (n=19) and DC guardian (n=54) overall ratings of current living situation by reporting year

## Health Status

The study also examined health status outcomes such as the need for medical and behavioral health supports and mortality using the NJCAT tool.

The measure of the need for medical supports considers three levels of medical need.[33] As shown Figure 10, both populations predominantly need specialized medical care, but compared to the community residents, a greater percentage of DC residents needed the more intensive specialized on-site nursing care. These differences were statistically significant.[34]

Among the 66 community residents with completed NJCATs both years, there was a statistically significant difference in medical supports scores in Year 3 compared to Year 1. The category with the largest change was specialized on-site nursing which had a 10.6 percentage point increase. The 181 DC residents with completed NJCATs both years also showed statistically significant differences in medical supports scores from Year 1 compared to Year 3. The category with the largest change was specialized on-site nursing with a 2.8 percentage point decrease.

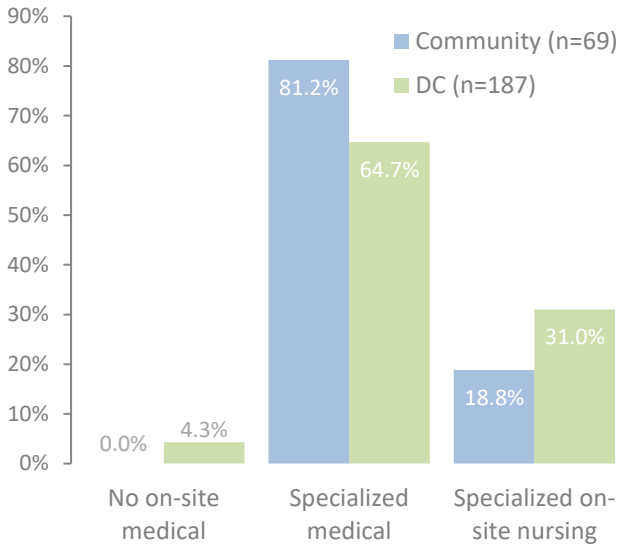


***Figure 10*** Medical assistance by residential placement type, Year 3

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 most DC residents needed no on-site 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

[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.

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

than among those who moved to a developmental center. These differences were statistically significant.[36]

Within the community residents, there was a statistically significant difference in behavioral supports scores in Year 3 compared to Year 1. The category with the largest change was no on-site supports which decreased by 13.6 percentage points. The DC residents also showed statistically significant difference in behavioral supports scores from Year 1 compared to Year 3. The magnitude of change for DC residents was less than community residents. There were modest increases in the percentage of individuals needing less behavioral supports and a five percent decline of those needing formal supports.

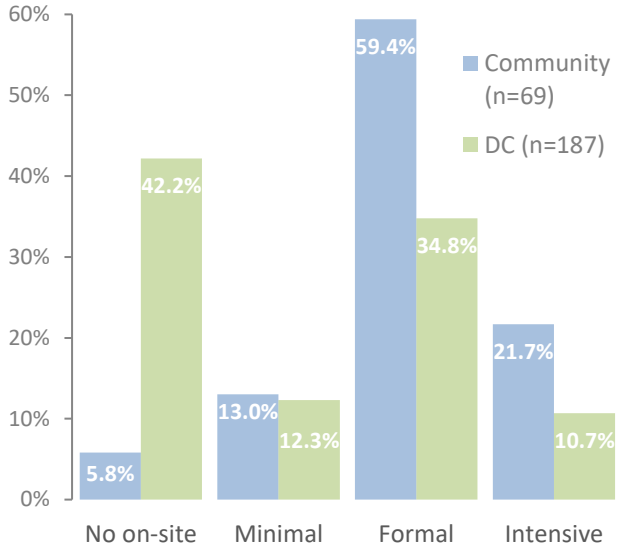


***Figure 11*** Need for behavioral supports by residential placement type

## Mortality

Among the 77 individuals living in the community at the start of the report period, three (3.9%) passed away in Year 3.[37] All three deaths resulted from natural causes including sepsis due to aspiration pneumonia, acute respiratory failure and cardiopulmonary arrest.

Three (1.5%) of the 204 individuals who were residing in other developmental centers at the start of the report period passed away.[38] All three deaths during Year 3 were due to natural causes including sepsis, seizure disorder, aspiration pneumonia, ischemic myocardial arrhythmia, cancer and acute renal failure[39].

## 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 short-

[36] Per analyses (using Pearson's chi-square).
[37] One individual was residing in hospice, one individual was discharged after a hospitalization to their own home and another was residing in a nursing home at the time of death.
[38] One individual was in inpatient hospice after a hospitalization at the time of death.
[39] Commonly, there are multiple causes of death listed.

age 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 standarized. 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 two separate law enforcement related incidents. One former Woodbridge DC resident was involved in the first incident and two Woodbridge residents in the other. Plans of correction were put in place and polices were appropriately amended to address future issues.

This concludes the Woodbridge DC closure evaluation for the third annual report (covering the third year post-closure). The fourth annual report out of five will cover the Year 4 period from January 8, 2018 through January 7, 2019.

# Appendix A: Family Guardian Survey

**Family and Guardian Survey - Woodbridge Developmental Center Residents in Community Placements - Year 3**

## 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 data from a variety of sources, including 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 may have been contacted last year for the second post-Woodbridge survey. You will receive these surveys annually for two more years as stipulated in the legislation. Even if you did not receive the previous 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.

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 3

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

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

_____

**3. Have you had contact with your relative 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. 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. 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.

**11. Do you have any additional comments?**

◯ Yes ◯ No

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. The first closure report can be accessed at https://bit.ly/2vYLgav or a paper copy can be requested by contacting

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