Woodbridge Developmental Center Year Five Closure Report

NJ DHS Office of Research, Evaluation & Special Projects

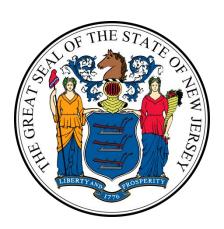


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Introduction

In 2006, the State Legislature required the New Jersey Department of Human Services' (NJ DHS) Division of Developmental Disabilities (DDD) to "develop a plan with established benchmarks to ensure that within eight years of implementation, each resident in a State developmental center who expressed a desire to live in the community and whose individual habilitation plan so recommends, is able to live in a community-based setting." 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 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 fifth 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 5. 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/JSOImPlanFinal.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.

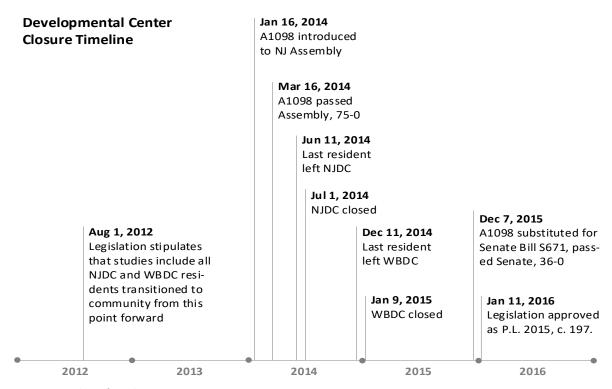


Figure 1 Timeline of DC closure

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 fifth report cover the period from January 8, 2019 until January 7, 2020. At the start of that time period, there were 267 members remaining in the cohort. Sixty-six 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, between August *Table 1* Cohort attrition

Cohort Attrition	Year 1	Year 2	Year 3	Year 4	Year 5
Individuals at the start of the report period	333	295	284	278	267
Pre-placement deaths	10				
Deaths	26	11	6	11	14
Discharges	2				

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, six passed away during Year 3 of the report, January 8, 2017 to January 7, 2018 and eleven passed away during Year 4 of the report. The fifth year of the report ended with 253 individuals due to 14 deaths during the fifth year.

Residential Settings

At the start of the report period, there were 267 former Woodbridge Developmental Center residents. A total of 190 individuals or 71.2% of the 267 former Woodbridge Developmental Center residents were residing in other developmental centers.⁶

Of the remaining 77 residents, 72 were living in the community. Four residents were in Skilled Nursing Facilities (SNF) and one individual was in a State Psychiatric Hospital after previously residing in a Developmental Center. This report focuses on the 190 individuals residing in developmental centers and the 72 persons living in the community.

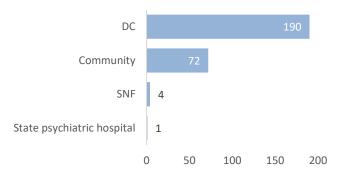


Figure 2 Placements from Woodbridge as of 1/8/2019 by type

Table 2 DC residents at start of report period by placement

Developmental Center	N	%
Woodbine	47	24.7%
Vineland	43	22.6%
New Lisbon	39	20.5%
Green Brook	34	17.9%
Hunterdon	27	14.2%
Total	190	100.0%

Of the 190 individuals from Woodbridge

who were living in Developmental Centers at the start of the report period, 47.4% resided in either Woodbine or Vineland. An additional 20.5% resided in New Lisbon and about 17.9% and 14.2% were living in Green Brook and Hunterdon, respectively.

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

Persons

The 267 former WBDC residents who were cohort members in January 2019, were more likely to be male (56.9%) and between 55 and 64 years old (49.4%). The mean age of the population was 60.3 years.

Table 3 Characteristics of Woodbridge residents on January 8, 2019 (n=267)

Characteristics	Year 5
Gender	
Male	56.9%
Female	43.1%
Age Group	
22 - 44 years	5.2%
45 - 54 years	16.5%
55 - 64 years	49.4%
65+ years	28.8%

Placement decisions were approved ___65

by the residents' guardians. Of the 190 former residents of Woodbridge who were living in other developmental centers at the start of the fifth year of the study, 146 or 76.8% had private guardians, primarily parents⁷ and siblings, but also including aunts/uncles, cousins, and other family members. Less than one-fourth (42 or 22.1%) had state guardians; two consumers were their own guardian.

Among the 72 former Woodbridge residents living in community settings at the start of Year 5, private guardians also were more common with 59.7% of the residents with community placements having family guardians, predominantly parents or siblings. A total of 36.1% of community residents had state guardians and three were their own guardian.⁸

Table 4 Guardians of DC and community residents by study year

Guardian Type by	Υ	ear 1	Ye	ear 2	Yea	ar 3	Yea	r 4	Ye	ar 5
Placement	N	%	N	%	N	%	N	%	N	%
Developmental Center	236		212		204		200		190	
Private (Family)	179	75.8	164	77.4	159	77.9	153	76.5	146	76.8
State Guardian	56	23.7	46	21.7	43	21.1	43	21.5	42	22.1
Self	1	0.4	2	0.9	2	1.0	4	2.0	2	1.1
Community	83		80		77		73		72	
Private (Family)	50	60.2	49	61.3	49	63.6	44	60.3	43	59.7
State Guardian	33	39.8	31	38.8	26	33.8	26	35.6	26	36.1
Self					2	2.6	3	4.1	3	4.2

There were five guardianship changes from Year 4 to Year 5 for the DC residents. Two individuals had a private guardian in Year 4 and a State guardian in Year 5. Two individuals were their own guardian in Year 4 and a private guardian in Year 5. One individual had a State guardian in Year 4

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 5, two had a private guardians and the other had a state appointed gaurdian at the time of death.

and a private guardian in Year 5. There were no guardianship changes for the community residents.

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, 2019 through January 7, 2020. 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.

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, two or 2.8% of the 72 individuals residing in community placements at the start of the report period experienced residential movements in Year 5. In both cases, only one move occurred. Both individuals moved from a community placement to another community placement managed by a different provider. Of the 190 Woodbridge residents who were placed in other developmental centers, four, or 2.1% moved in Year 5. Three individuals were placed in skilled nursing facilities and one moved from one developmental center to another.

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.

None of the Woodbridge residents placed in the community was admitted to a state psychiatric hospital during the fifth year of the study. ¹¹ The individual who was admitted to a state psychiatric hospital from a DC in Year 4 and was still residing in the state psychiatric hospital on the first day of Year 5 was moved back to a DC within the Year 5 report period.

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

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 75.9 weekly direct staffing hours with a range from 51.2 to 92.8 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; the more residents in a placement, the higher the number of direct care staffing hours. However, other factors may come into play in determining staffing levels. Two placements can be managed by the same agency and could have different per capita hours of staffing; 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

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, 2019 through January 7, 2020.

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, 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 = .866

programs, staffing is provided; similarly, additional staff is hired on an as needed basis for special activities or to ensure adequate coverage.

Of the 72 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 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.

Fifty-seven individuals partici pated 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)	57	79.2
State Plan Funded Medical Day Programs	8	11.1
In-home supports	7	9.7
Total	72	100.0

Eight 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.

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

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. ¹⁵ 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

¹⁵ 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/human-services/ddd/documents/supports-program-policy-manual.pdf

examination."¹⁶ 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 59 of 60¹⁷ individuals or about 98.3% had an annual medical examination during Year 5. One individual was late to complete their annual physical date during the report period.

The licensing standards for residents of group homes as set forth in New Jersey's Administrative Code¹⁸ 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.

Sixty-eight individuals or 98.6% of the 69 individuals in the community with available dental records received dental care during Year 5. Of the 68 with dental care, 64 were annual dental exams while another 4 individuals had some other type of dental claim. One individual did not receive annual dental care during the reporting period because the individual was on a waiting list for a dental provider.

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. In these situations, Emergency Medical Technicians (EMTs) and police typically respond, but the individual, depending on circumstances may or may not be transported to an emergency room, because not all Danielle's Law coded-incidents or incidents where 9-1-1 was called involve life-threatening emergencies as subsequently determined by medically trained personnel. Staff members often act out of an abundance of caution and contact 9-1-1, regardless of the particulars, because they face a \$5,000 fine when a "covered" incident is not reported and may not feel equipped to judge the severity

¹⁶ See http://www.state.nj.us/humanservices/ool/documents/10 44A eff 4 18 05.pdf

¹⁷ Twelve individuals documentation was not available at the time of data collection. Documentation was not available due to individuals moving to Skilled Nursing Facilities and individual's passing away before data could be recorded.

¹⁸ Ibid.

¹⁹ See https://www.nj.gov/humanservices/ddd/providers/providerinformation/danielle/

of the event.20

During Year 5, thirty, or 41.7% of the 72 individuals living in the community, had one or more incidents that triggered a 9-1-1 call in compliance with Danielle's Law. The total number of Danielle's Law-coded incidents was 82. All 82 incidents were medical in nature.

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 72 residents living in

community placements, 46, or 63.9%, had emergency room visits during Year 5. The number of

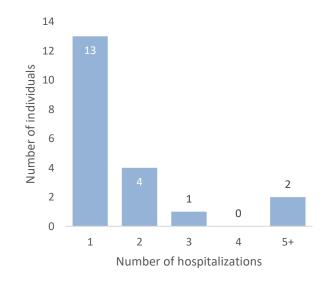
visits ranged from one to more than seven, with a mean of 3.04 (among those with visits). The most common reasons given for the emergency room visit were head, ear or eye laceration, contusion, abrasion or other injury; gastrointestinal complications; and other related injuries, lacerations, contusions, fractures and abrasions not involving the head.

Of the 72 Woodbridge residents living in the community, 20 or 27.8% had one or more hospitalizations for medical conditions. Community residents had a total of 39 hospitalizations. Leading reasons for hospitalizations included sepsis and epilepsy or seizures.

Table 6 ER visits during Year 5

# of ER visits	N	Percent	
0	26	36.1%	
1	17	23.6%	
2	9	12.5%	
3	6	8.3%	
4	6	8.3%	
5-6	3	4.2%	
7+	5	6.9%	
Total	72	100.0%	

Table 7 Number of hospitalizations in Year 5



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:

²⁰ In place of the previously used UIRMS, the New Jersey Incident Reporting Management System, (NJIRMS) was rolled out on July 9, 2018. In the new NJIRMS, a Danielle's Law code was no longer used, and instead a "911 called" box was utilized. Then on September 25, 2018 in order to track incidents more accurately in NJIRMS, a life threatening emergency box was also added. The addition of both boxes helps more accurately indicate what incidents fall under Danielle's Law, because not all 911 calls are necessarily for life threatening emergencies. The number of incidents reported during this period should not be compared to previous reporting periods due to this change.

- 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 5 and compares scores for individuals placed in the community to those placed in other DCs. Data were available for 54 of the 72 community residents and 166 of the 190 DC residents. Within group comparisons are also made between Years 1 and 5, including determination of statistically significant differences in these scores between those who were in DCs in both Years 1 and 5 (n=162) and those who were in community placements in both years (n=51). For this final report, individuals who did not move and completed NJCAT's for Years 1, Year 2, Year 3, Year 4 and Year 5 were used to determine changes over the five years. There were 147 individuals living in other developmental centers and 42 individuals living in the community with NJCAT's completed for all 5 years of the study.

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

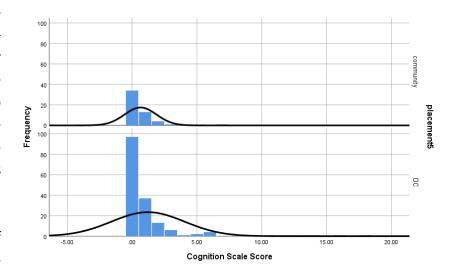


Figure 3 Cognition scores of community and DC residents, Year 5

scale scores for the community residents was 0.65 and for the DC residents was 1.22.

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 3 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.

A total of 51 individuals in the community and 162 in the DC's had NJCAT data for Years 1 and 5. Comparisons between Year 1 and Year 5 average cognition scores for individuals in the community and DC

Table 8 Percentage with a cognitive limitation by type of residence

Limitation	Community	DC
No substantial limitation	0.0%	0.6%
Substantial limitation	100.0%	99.4%

showed a decline in cognition scores in Year 5²². As Shown in Figure 4, cognition scores for the community residents consistently remained lower than the DC residents. The community residents saw a substantial increase in Year 3 while the DC residents saw only a minimal increase that year. Following Year 3, the community residents dropped back down to an average lower

²² Statistical significance could not be tested due to the lack of variability in scores over time and low sample sizes.

than Year 2. The DC residents average was the highest for Year 1 then saw a statistically significant²³ decrease in Year 2 which increased slightly every year thereafter. The increase from Year 1 to Year 3 for the DC residents were statistically significant. Both the DC and community cognition scores declined from Year 1 to Year 5 though the declines were not significant.

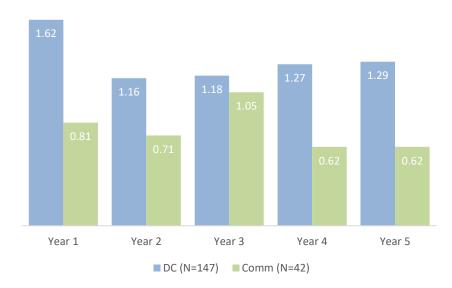


Figure 4 DC and Community average cognition scores over time

The basic self-care need scale consisted of 14 items. Scores for each item ranged from 0 to 3, with 0 indicating the individual has not done the activity, 1 indicating that the individual requires lots of assistance to perform the activity, 2 indicating that the individual can perform the activity with supervision, and 3 indicating the individual can perform the activity independently. Items pertained to feeding, drinking, chewing/swallowing, toileting, dressing, moving around, washing hands/face, brushing hair, adjusting water temperature, drying body after bathing, tying shoes (using laces or Velcro), and using tissues to wipe/blow nose. Total scores could range from 0 if individuals were unable to perform any of the tasks to 42 among individuals able to perform all tasks independently.

²³ Significance was based upon calculation of a Greenhouse-Geisser repeated measures ANOVA, sphericity not assumed.

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The average scale score for the community residents was 7.44 and for the DC residents was 10.95.

The distributions in Figure 5 show that the modal group of individuals residing in both the community and the developmental centers had scores of zero. The DC residents had significantly higher basic self-care scores compared to the community.

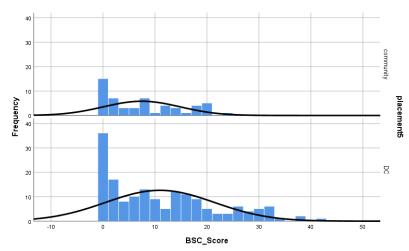


Figure 5 Basic self-care scores of community and DC residents, Year 5

Further, 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 9 Limitation in basic self-care by type of residence, Year 5

Limitation	Community	DC
No substantial limitation	0.0%	1.8%
Substantial limitation	100.0%	98.2%

For DC residents meaningful comparison of Years 1 and 5 self-care scores could not be done due to too much spread in the scores. Community residents' self care scores decreased significantly from Year 1 to Year 5. Fifty of the 51 individuals residing in the community during both years had a substantial self-care limitation; all 51 had a substantial limitation during Year 5. Twelve, or 7.4% of DC individuals did not have a substantial self-care limitation in Year 1; only three or 1.9% had no substantial limitation during Year 5. A large majority in both years had substantial self-care limitations. When comparing means over time, the DC residents did not change significantly over time and were consistently higher than the community averages. The community self-care scores significantly changed over time²⁴. There was a significant decrease from Year 1 to 2, Year 1 to 5 and Year 4 to 5. There was a significant increase from Year 2 to 3.

²⁴ Significance was based upon calculation of a repeated measures ANOVA, sphericity assumed.

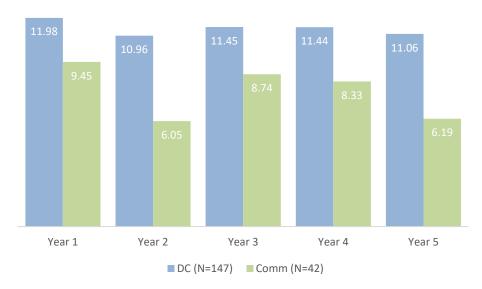


Figure 6 DC and community average self-care scores over time

This question captured mobility: "Does (name) walk independently without difficulty, without using a corrective device, and/or without receiving assistance." Analysis of Year 5 data shows 16.7% of the community residents and 24.1% of the DC residents were able to walk independently in Year 5. These differences were not statistically significant between community and DC cohorts.

Comparisons of Years 1 and 5 suggest very slight differences among community and DC residents. Statistical testing was not feasible for the community residents given the small sample size. Thirty-five DC residents were able to walk independently during Year 1 and 39 residents in Year 5. This difference was statistically significant²⁵, but because changes in ability to walk independently improved for some individuals but worsened for others; there is no direction of statistical significance.

These statistically significant differences between the DC and community residents scores over time should be examined further to understand what is an artifact of the respondent, a real difference in the cohorts or other factors related to services and/or living arrangement.

²⁵ There were six individuals who were not able to walk independently in Year 1 but could walk independently in Year 5. There were four individuals who were able to walk independently during Year 1 but could not in Year 5. There were eight individuals who were not able to walk independently in Year 1 but were able to in Year 5.

Consumer Interviews

Consumers were interviewed in Years 1, 2, 3 and 4 in order to determine their satisfaction with residential placements and whether they would prefer to live in a developmental center. Interviews were completed after the conclusion of each reporting year and due to the COVID-19 Pandemic beginning in March 2020, interviews for Year 5 were not completed in order to reduce the risk and exposure to the former DC residents who live in group homes and supervised apartments.

Family Contacts

Information about contacts residents have Table 10 Family involvement among community residents with family was obtained from the family/guardian surveys and staff members from individual's residences. There was fifteen individuals for whom frequency of family contact was not available. Where data were available, results show that 11 of the 57 placed in the community with available information had no family.

Of the remaining 46 with family and information regarding the frequency of contact, 30 had at least annual contact and 16 had no contact during the annual reporting period. Of the 30 with annual contact, 8 had at least weekly contact; 8 had at least monthly contact; 14 had at least once during the year²⁶.

Family involvement	N	%
Family involved	46	63.9%
No family	11	15.3%
Missing ALA information	15	20.8%

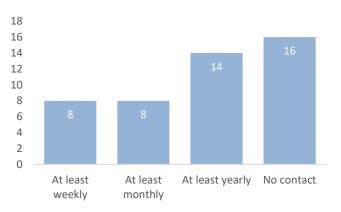


Figure 7 Frequency of family contact (N=46)

Fifty-six of the 56 community residents

for whom frequency of peer contacts were available had access to peers, primarily on a daily basis.

²⁶ Data were collected a year after the report period ended and during the COVID-19 pandemic. Some group home staff noted changes in family contact due to the pandemic.

Year 5 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 survey²⁷ was mailed to the family/guardians of everyone (n=31) 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.

As of November 2020^{28} , 23 family/guardians of 31 former Woodbridge residents living in the community had responded to the survey, a response rate of 74.2%. ²⁹ Twenty-two respondents (95.7%) were related to the former Woodbridge resident. Respondents were primarily either siblings (56.5%) or parents (26.1%). Other family members included an aunt or uncle and cousin (13.0% combined).³⁰

Most (72.7%) of the respondents (n=16) had visited former Woodbridge residents in their community placements.³¹ All but two of the individuals that responded to the question had some form of contact with their loved one. Nine respondents contacted staff at the residence. Five respondents had contact with residents by phone or email. The totals summed to more than 22, because respondents could have multiple methods of contact. For example, four individuals both visited and had contact via phone or email. Of the nine respondents who contacted staff, four 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.³²

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

²⁷ See Appendix. Items were based upon surveys conducted of previous institutional closures in New Jersey.

²⁸ The survey was sent by mail shortly before the COVID-19 pandemic began affecting New Jersey. Response rate did not seem to be impacted, however, surveys were being completed and returned during the peak of the pandemic which may have impacted guardian satisfaction with programs and services.

²⁹ Where there were more than one respondent for one individual, one survey for each individual was chosen at random.

³⁰ Changes in guardianship relationships from the previous reports may reflect differences in who responded to the survey and which dupicates were chosen at random.

³¹ One individual skipped this question. There were 22 responses to the question about contact with their loved one.

³² The surveys were sent to guardians during the COVID-19 pandemic which may have reduced physical visitations with former residents due to social distancing measures and statewide restrictions.

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.

Average scores for each of the 13 items fall between 3.86 and 4.74 with the staff responsible for their care and personal safety rated the highest for the community ratings.³³

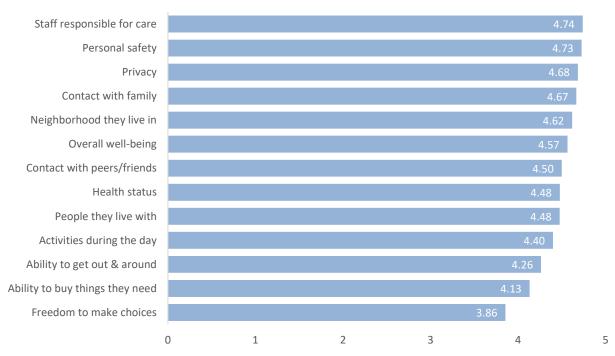


Figure 8 Family guardian perceptions of consumer's current living situation

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.

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³³ The legislation specifically mentions personal safety and health status, both of which are rated over 4.0.

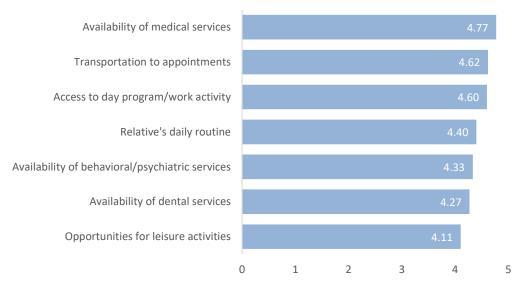


Figure 9 Average ratings of programming and services (higher scores indicate greater satisfaction)

High reported satisfaction in programming and services as shown in Figure 9 was evident in the item averages, which ranged from a low of 4.11 to a high of 4.77, where a "5" indicates the respondent is "very satisfied." The rating for average satisfaction with availability of medical services at 4.77 was the highest for any of the community programming ratings.

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

Nineteen out of twenty-three (82.6%) guardians rated a significant or somewhat improvement in their relatives well-being. One (4.3%) gaurdian rated their well-being unchanged and three (13.0%) rated somewhat or significant decline. Guardians average change in well-being was between somewhat improvement and significant improvement, with an average score of 4.43.

Table 11 Community guardian perception of relative's change in well-being compared to Woodbridge DC (n=23)

Change in well-being	N	%
Significant/somewhat improved	19	82.6%
Unchanged	1	4.3%
Significant/somewhat declined	3	13.0%

Year 5 Family/Guardian Survey: Community and DC Comparisons

A comparison was made between the perceptions of overall quality of life of private guardians of the 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 127 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 previously. Family/guardians who did not respond to the initial mailing received a postcard reminder followed by up to three phone calls.

As of November 2020, surveys had been received from 98 family/guardians. These included nine residents with two family respondents each; one survey for each individual was chosen at random, leaving 86 respondents and a response rate of 70.1%. All but one of the respondents were family members, primarily siblings (57.3%) or parents (31.5%); 10.1% of the respondents were aunts/uncles, cousins and other family members.

Asked to rate how their relative is doing Table 12 Guardian perception of relative's well-being overall. 21 of 23 (91.3%) guardians of community residents and 79 of 89 (88.8%) guardians of other developmental center residents reported their

How relative is doing everall	Community	DC
How relative is doing overall	(n=23)	(n=89)
Excellent/Good	91.3%	88.8%
Fair/Poor	8.7%	7.9%
Don't know/Missing	0.0%	3.4%

relative was doing "Excellent/Good". Two (8.7%) guardians of community residents and seven (7.9%) guardians of other developmental centers rated their relative as doing "Fair/Poor." Three (3.4%) 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. However, with a few exceptions, none of the results were statistically significant. Family/guardians of community residents were statistically significantly more worried about staff turnover while DC guardians were more happy with their relatives freedom to make choices.

Table 13 Changes to individual's situation over the past year

Types of changes	Commu	ınity (n=23)	DC (n=89)	
Types of changes	N	%	N	%
Moved to a different residence	2	8.7%	16	18.0%
Has a different roommate	1	4.3%	15	16.9%
Has different staff caring for him/her	12	52.2%	22	24.7%
Attends a different day program	1	4.3%		

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 (52.2%); the least frequent changes reported were has a different roommate and attending a different day program (8.6% combined). Guardians of developmental center residents also reported that the most frequent change was in staff caring for the relative (24.7%) and the least frequent change was a change in roommate (16.9%).

Family/Guardian Survey: Year 1 and Year 5 Comparisons

The results from surveys of family guardians who completed a survey for both the first and the fifth report periods were compared. There were 54 family members of individuals living in DCs and 12 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."

Table 14 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.

		Communi	ty (n=12)			DC (n	=54)	
Community & Social Interaction	Year 1 Mean	Year 5 Mean	Differ- ence	N	Year 1 Mean	Year 5 Mean	Difference	N
Contact with family	4.80	4.90	0.10	10	4.73	4.34	-0.39	41
Personal Safety	4.82	4.82	0.00	11	4.46	4.44	-0.02	50
Privacy	5.00	5.00	0.00	10	4.64	4.61	-0.04	28
Neighborhood they live in	5.00	4.82	-0.18	11	4.72	4.64	-0.08	39
Staff responsible for care	5.00	4.75	-0.25	12	4.76	4.88	0.12	49
Ability to buy things they need	4.29	4.00	-0.29	7	4.06	4.47	0.41	17
People they live with	4.90	4.60	-0.30	10	4.51	4.54	0.02	41
Health status	4.92	4.58	-0.33	12	4.43	4.43	0.00	46
Activities during the day	4.73	4.36	-0.36	11	4.69	4.44	-0.25	36
Contact with peers/friends	4.80	4.40	-0.40	10	4.52	4.32	-0.20	25
Overall well-being	5.00	4.58	-0.42	12	4.49	4.61	0.12	49
Ability to get out & around	4.90	4.10	-0.80	10	4.47	4.25	-0.22	36
Freedom to make choices	4.43	3.57	-0.86	7	4.44	4.69	0.25	16

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

contact with family higher in Year 5 than Year 1 while their personal safety and privacy remained the same in Year 1 and Year 5. The remaining ratings decreased four years later. Despite these numeric decreases, all but one ratings fell between somewhat happy and very happy. ³⁴

DC guardians rated 5 of the 13 items higher in Year 5 than Year 1. The most improvement in happiness was reported for the consumers' ability to buy things they need and freedom to make choices. Perceived happiness with their ability to get out and around, contact with peers and friends, activities they have during the day and neighborhood they live in declined in both placement settings.

Table 15 Comparison of average family guardian ratings of satisfaction with aspects of current living arrangement, Year 1 and Year 5. Note: Sample sizes vary by item due to variations in item response; the term "mean" is synonymous with the average score.

Services		Comm	unity			D	C	
	Year 1	Year 5	Difference	N	Year 1	Year 5	Difference	N
	Mean	Mean			Mean	Mean		
Availability of medical services	4.91	4.91	0.00	11	4.66	4.76	0.10	50
Transportation to appointments	5.00	4.55	-0.45	11	4.67	4.71	-0.05	42
Access to day program/work activity	4.91	4.45	-0.45	11	4.42	4.44	0.02	34
Availability of behavioral/psychiatric services	4.89	4.22	-0.67	9	4.63	4.66	0.03	35
Daily routine	4.90	4.20	-0.70	10	4.58	4.60	0.02	40
Availability of dental services	4.91	3.91	-1.00	11	4.57	4.66	0.09	47
Opportunities for leisure activities	4.90	3.70	-1.20	10	4.51	4.49	-0.03	35

Each family guardian rated his or her satisfaction with aspects of the resident's programming, including access to medical, dental and behavioral health services, transportation, day program, and daily routine and leisure. Average ratings for Year 5 are compared to Year 1. With two exceptions, all averages for Year 5 across all aspects were rated between "somewhat satisfied" and "very satisfied" by both the community and DC guardians. Community gaurdians average ratings for availability of dental services and opportunities for leisure activities between "neither satisfied nor dissatisfied" and "somewhat satisfied". Community guardians rated availability of medical services the same in the fifth year as the first year. The other six items were rated lower

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³⁴ 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, about half of the ratings were unchanged or increased. The decrease in community ratings may reflect regression towards the mean since higher ratings are most apt to fall.

the fifth year than the first year. The DC guardians rated transporataion to appointments and opportunities for leisure activites lower the fifth year while all of the rest of the ratings increased. The largest increases in programming satisfaction of family/guardians of DC residents were availability of medical services and availability of dental services. Overall the community guardian satisfaction in the first year was higher than the DC satisfaction in the first year. It is possible that in the first year of the study, the community guardians were comparing community living to life at the DC and over time that comparison switched from life at the DC to what they see as the standard of care and/or the possibilities expected in the community.

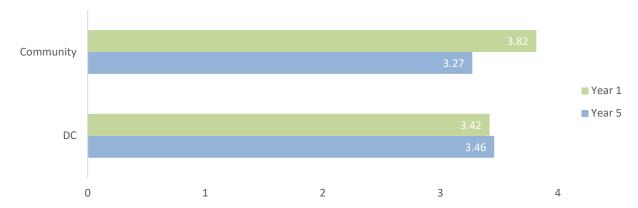


Figure 10 Average community (n=11) and DC guardian (n=50) overall ratings of current living situation by reporting year

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 from Year 1 to Year 5 by 0.04 and the community decreased by 0.55.

Health Status

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

The measure of the need for medical supports considers three levels of medical need. ³⁵ As shown in Figure 11, 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 not statistically significant. ³⁶

Among the 51 community residents with completed NJCATs for both years, statistical significance from Year 5 compared to Year 1 could not be determined due to the lack of variability in the responses. The category with the largest change was specialized on-site nursing which had a 7.9 percentage point increase which reflected five individuals who went from

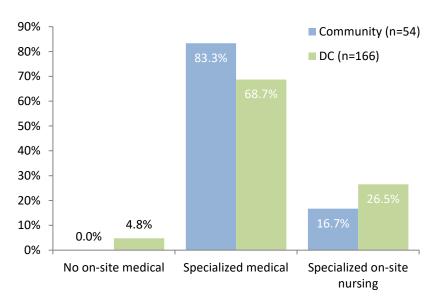


Figure 11 Medical assistance by residential placement type, Year 5

specialized medical in Year 1 to specialized on-site nursing in Year 5. For the 162 DC residents with completed NJCATs in both years, statistical significance in medical supports scores from Year 1 compared to Year 5 also could not be determined also due to the lack of variability in responses. The categories with the largest change was specialized medical with a 5.5 percentage point increase and specialized on-site nursing with a 5.5 percentage point decrease.

The Behavioral Supports Level has scores ranging from 1 to 4, with higher scores associated with behaviors requiring more intensive support and environmental modifications.³⁷

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

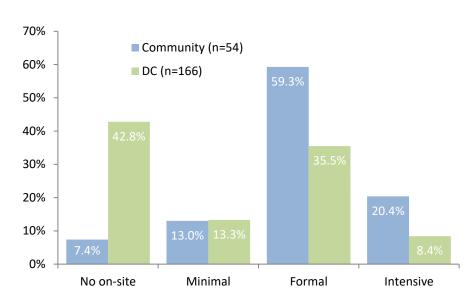
³⁵ Analysis of these scales showed both high test-retest reliability using the same raters at two intervals and good inter-rater reliability. See Lerman, P., Apgar, D.H. and Jordan, T. (2009). The New Jersey Developmental Disabilities Resource Tool DDRT: History, Methodology and Applications. Developmental Disabilities Planning Institute, New Jersey Institute of Technology, 196-197.

³⁶ Per analyses using Pearson's chi-square.

³⁷ Lerman, et al., op. cit., 188-190.

than among those who moved to a developmental center. These differences were statistically significant.³⁸

Statistical significance testing of behavioral health supports from Year 1 to Year 5 was not feasible for the community residents or the DC residents due to lack of variability in responses. For the community residents, the category with the largest



change was formal Figure 12 Need for behavior

Figure 12 Need for behavioral supports by residential placement type, Year 5

supports which increased by 17.6 percentage points. The magnitude of change for DC residents was less than community residents. There was a 5.5 percent decline in those needing formal supports and a 5.5% increase in those needing no on-site supports.

Mortality

Among the 72 individuals living in the community at the start of the report period, three (4.2%) passed away in Year 5. Two deaths resulted from natural causes including cardiopulmonary failure and aspiration pneumonia. One death was ruled accidential and the cause of death was complications of hypoxemia due to aspiration, or choking.

Ten (5.3%) of the 190 individuals who were residing in other developmental centers at the start of the report period passed away. All ten deaths during Year 5 were due to natural causes including sepsis, septic shock, respiratory failure, shock due to sepsis, pneumonia, urosepsis, severe dysphagia and Rhett's Syndrome.

One individual who was living in a SNF at the start of the report period passed away during year 5. This individual lived in the community at one point after the closure of Woodbridge DC and their death was natural due to cardiopulmonary arrest.

³⁸ Per analyses (using Pearson's chi-square).

Unusual Incidents

The Department of Human Services' Incident Reporting and Management System (NJIRMS) captures information on a range of unusual incidents including operational (e.g., a minor fire extinguished by staff), operational breakdowns (when an outage or disruption poses a threat to health and safety and/or impacts facility operations), unexpected staff shortages (if the shortage results in the inability to safely evacuate residents or if appropriate levels of supervision cannot be maintained) or criminal activity³⁹. Regulations stipulate that criminal activity involveing 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 NJIRMS 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. This review of NJIRMS data yielded one incident with law enforcement involvement. This incident involved one former Woodbridge resident and appropriate administrative action has been taken.

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

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³⁹ In July 2018, a new incident reporting system, NJIRMS was rolled out. In the old system, UIRMS, any time there was a report of a potential criminal act it was reported as criminal activity. In the new system, criminal activity is only used when charges are pressed. The number of reported incidents during this period should not be compared to other reporting periods due to this change in systems.

Appendix A: Family Guardian Survey



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

INTRODUCTION

In January 2016, the Legislature passed a law that requires the New Jersey Department of Human Services (DHS) to report on the well-being of individuals who have moved from 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 various sources, including information from family members and/or guardians about former residents' quality of life in their new living arrangements.

You have been identified as a family member and/or guardian of an individual who moved from 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 in past years for previous post-closure surveys. Even if you did not receive the previous surveys, you can still complete this one. As stipulated in the legislation, this will be the final survey. Your answers should reflect your perceptions of how well your relative has done over the past year.

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

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

If you have any questions, please contact

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



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

SURVEY

r Relative's Initials:		
		elated to the person who was impacted by the c
Grandparent	lopmental Center? I am: (Se	Niece/Nephew
Parent/Stepparent		Cousin
Sibling (Brother/Sist	er/Brother In-law/Sister In-law)	Friend/Family friend
Aunt/Uncle		
Other (please speci	fy)	
3. Have you had con past year? (Check al	<u>-</u>	he or she has been in a community residence i
There was indirect of	contact (e.g., calls to staff)	
Yes, we communicate	ted by phone or email	
Yes, I visited him or	her	
	rect or indirect contact	

4. How frequently have you had contact w best reflects the amount of contact)	ith your relative in the past year? (Select the answer tha
Daily	
Weekly	
Monthly	
Quarterly	
Annually	
No contact in the past year	
Other (please specify)	
the past year? (Check all that apply)	living situation changed in any of the following ways ov
Moved to a different residence	Has different staff caring for him/her
Has a different roommate	Attends a different day program

	Very happy	Somewhat happy	Neither happy nor unhappy	Somewhat unhappy	Very unhappy	NA or Don't know
The people they live with	\circ	\circ	\circ	\circ	\bigcirc	\circ
The staff responsible for their care	\circ	\circ	\circ	\circ	\circ	\circ
The activities they have during the day	\circ	\circ	\circ	\circ	\circ	\circ
Their ability to get out and get around	\circ	\bigcirc	\circ	\circ	\circ	\circ
The neighborhood they live in	\circ	\circ	\circ	\circ	\circ	\circ
Their personal safety	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
The contact they have with you or other family members	0	0	0	0	0	0
The contact that they have with peers and friends	0	0	\circ	0	\circ	0
Their freedom to make choices	0	\circ	\circ	\circ	\circ	\circ
Their ability to buy things they need	0	\circ	\circ	\circ	\circ	\circ
Their privacy	\bigcirc	\bigcirc	\bigcirc	\circ	\circ	\bigcirc
Their health status	\bigcirc	\bigcirc	\circ	\bigcirc	\circ	\bigcirc
Their overall well- being	\circ	\circ	\circ	\circ	\circ	\circ

esponse for each qu		of the follow	ring at your re	lative's <i>curre</i>	ent residence?	? (Select ONE
•	Very worried	Somewh worrie			particularly worried N	Not at all worried
Level of supervision	\bigcirc	\bigcirc			\bigcirc	
Preparation of staff to handle behavioral or medical problems	\circ	0			0	0
Staff turnover	\bigcirc	\bigcirc			\bigcirc	
Risk of abuse or neglect	0	0			\circ	\circ
				nly ONE answ	er for each a	uestion)
. How satisfied are	you with each (Somewhat	Ing? (Select of Neither satisfied nor	Somewhat	Very	Unsure or
. How satisfied are y	you with each o		Neither		-	
Your relative's daily		Somewhat	Neither satisfied nor	Somewhat	Very	Unsure or
Your relative's daily		Somewhat	Neither satisfied nor	Somewhat	Very	Unsure or
Your relative's daily routine Opportunities for		Somewhat	Neither satisfied nor	Somewhat	Very	Unsure or
Your relative's daily routine Opportunities for leisure activities Access to either a day program or work		Somewhat	Neither satisfied nor	Somewhat	Very	Unsure or
Your relative's daily routine Opportunities for leisure activities Access to either a day program or work activity Transportation to appointments or		Somewhat	Neither satisfied nor	Somewhat	Very	Unsure or
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		Somewhat	Neither satisfied nor	Somewhat	Very	Unsure or

Overall, how would you rate ONE)	how your relative is doing in their <i>current</i> living situation? (Select
Excellent	
Good	
Fair	
Poor	
Oon't Know	
10. How would you rate your r at Woodbridge Developmental	elatives well-being in the community <i>compared to</i> when they lived Center? (Select ONE)
Significantly improved	
Somewhat improved	
Unchanged	
Somewhat declined	
Significantly declined	
this survey?	ber to follow up with you directly regarding any concerns indicated on
Yes	○ No
	omments? If yes, please specify (use the back of the page if
,	
	ipation in the survey, your responses are valued and help DHS strengthen provided to constituents. Previous closure reports can be accessed at
	es can be requested by contacting