State of New Jersey

Department of Human Services

Woodbridge Developmental Center Year One Closure Report

NJ DHS Office of Research, Evaluation & Special Projects
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Commissioner

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Introduction

In 2006, the State Legislature required the New Jersey Department of Human Services' (NJ DHS) Division of Developmental Disabilities (DDD) to "develop a plan with established benchmarks to ensure that within eight years of implementation, each resident in a State developmental center who expressed a desire to live in the community and whose individual habilitation plan so recommends, is able to live in a community-based setting."[1] 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.

This report presents data for the first year following the closure of Woodbridge Developmental Center. It addresses the topics mandated in legislation focusing on persons, settings, services and outcomes. Contextual comparisons as feasible and appropriate are made between clients moved into community placements and those residing in developmental centers. Information was obtained from many sources and utilized varied methodologies including consumer and family surveys, specialized 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.

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

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

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

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

[5] Or State psychiatric hospital.

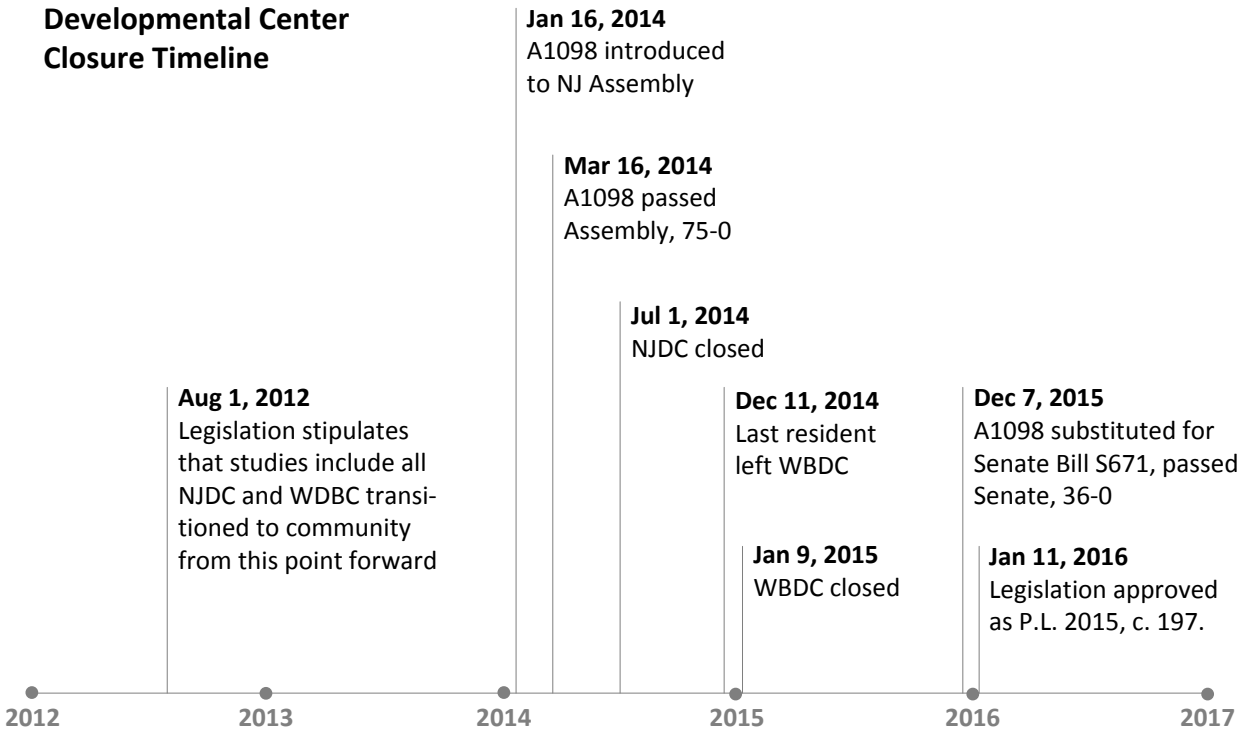

Figure 1 Timeline of DC closure

Woodbridge Developmental Center

This report focuses on study findings for 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 cover the period from August 1, 2012[6] until January 7, 2016, approximately one year after the facility closed. The information presented in this report will be updated on an annual basis for five years as mandated.

[6] August 1, 2012 was the date specified in the legislation for defining the placement cohort; the first placement was made on August 10, 2012.

Persons

Woodbridge Developmental Center was situated in suburban Woodbridge in Middlesex County. In August 2012, its 333 residents were more likely to be male (59%) and of middle age: the largest age group was between 45 to 54 years old (43%). The mean age of the population was 54.4 years.

Table 1: Characteristics of Woodbridge Residents on August 1, 2012 (n=333)

Characteristics	Percentage
Gender	
Male	59%
Female	41%
Age Group	
22 - 44 years	13%
45 - 54 years	43%
55 - 64 years	35%
65+ years	10%

Table 2: Guardians by placement type

Guardian Type by Placement	N	%
Developmental Center	236	-
Private (Family)	179	75.8%
State Guardian	56	23.7%
Self	1	0.4%
Community	83	-
Private (Family)	50	60.2%
State Guardian	33	39.8%

Placement decisions were approved by the residents' guardians. Of the 236 former residents of Woodbridge who were placed in other developmental centers, 179 or 75.8% had private guardians, primarily parents[7] and siblings, but also including aunts/uncles, cousins, and other family members. Somewhat less than one-fourth (56 or 23.7%) had state guardians, and one consumer was his/her own guardian. Among the community placements, private guardians also were more common with about 60% of the residents with community placements having family guardians, predominantly parents or siblings, while about 40% had state guardians.

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

Residential Settings

From August 2012 through December 2014, 236 individuals or 71% of the 333 Woodbridge Developmental Center residents were transferred to other developmental centers.[8] Of the remaining residents, 83 moved to the community. Another 10 died prior to the closure and 4 were discharged.[9] None of the Woodbridge residents placed in the community was subsequently admitted to a state psychiatric hospital.[10]

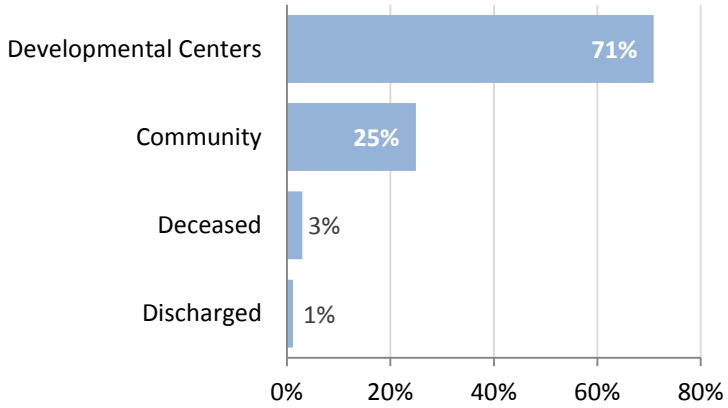

Figure 2: Placements from Woodbridge after August 1, 2012 by type

Of the 236 individuals from Woodbridge who were placed in other developmental centers, about 63% went either to Vineland or Woodbine. An additional 18% went to New Lisbon and about 11% and 8% were transferred to Green Brook and Hunterdon, respectively.

Table 3: Transfers to developmental centers

Developmental Center	N	%
Green Brook	25	10.6%
Hunterdon	18	7.6%
New Lisbon	43	18.2%
Vineland	76	32.2%
Woodbine	74	31.4%
Total	236	100.0%

Moves to Different Settings

A move or transfer consisted of a change that followed the original residential placement, e.g., from a developmental center into the community or from the community into a developmental center. Moves also occurred when residents were transferred from one community residential placement agency to another or from one developmental center to another. Additionally, moves occurred from either a developmental center or a community residential placement into

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

[9] Of the four who were discharged, two had family either residing or relocating out-of-state who arranged care for their relative closer to the family home. The remaining two individuals had terminal illnesses and were discharged to skilled nursing facilities for the time remaining to them.

[10] Former DC residents were cross-referenced with the Division of Mental Health and Addiction Services state psychiatric hospital database.

a Skilled Nursing Facility (SNF) as a permanent placement, related either to terminal illness or a chronic medical condition requiring nursing care.

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

- Changes among cottages at the same developmental center.[11]
- Movement to another community residence operated by the same agency.
- Hospitalizations regardless of duration (as these are not residential placements).
- Rehabilitation in a short-term, temporary skilled nursing or rehabilitation facility following hospitalization (with the goal of returning the individual to a residential placement).[12]

Based on this definition and analysis, 45, or 13.5%, of the 333 residents from Woodbridge experienced residential movements following their initial placement. For 44 of the 45, only one such move occurred. In one instance, the resident moved twice, first from one developmental center to another, and then from the developmental center to a SNF.

As seen in Figure 3, the majority of the moves that occurred were among developmental centers; 26 of the 46 moves, or 56.5%, were of this type.[13] Often these moves were made at the family's request in order to reduce the geographic distance between the DC resident and his or her family. Movement among community placement agencies occurred in six instances, or 13% of all moves. Three residents experienced movement

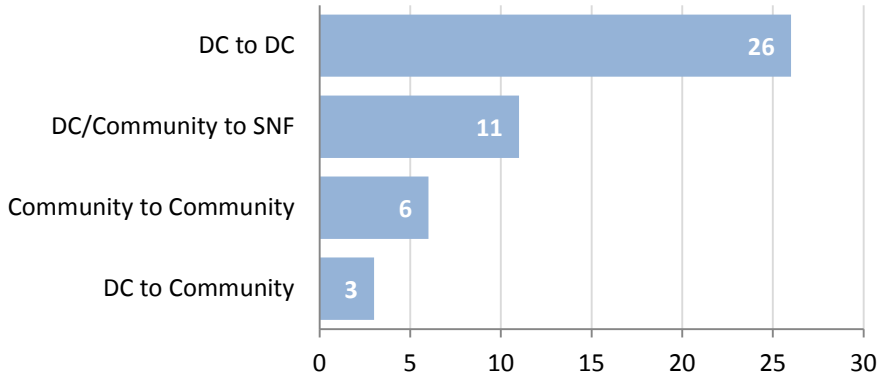

Figure 3: Types of placement moves (N=46)

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

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

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

from a developmental center to a community residential setting, a total of 6.5% of all moves. Finally, 11 moves, or 23.9%, entailed placement in a SNF from a developmental center or a community placement setting, with movement from either about equally likely to occur.

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. Proposed changes incorporated into the most recent Community Care Waiver renewal application will add several new services and rehabilitative therapies as available options.

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 random sample of ten was selected.[14] The per capita hours of direct service staffing in these placements was calculated and an average of 79.2 weekly direct staffing hours per capita and a range from 51.5 to 111 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.[15] However, other factors may come into play in determining staffing levels. Three of the homes were managed by the same agency and thus offer the best basis for comparison. In two instances, the weekly per capita hours were similar but the distribution of hours across shifts was different. In one home, a resident did not leave during the day for a weekday program or activity in part because that was not the pattern established while in residence at the developmental center. Thus, for this home there was a staff person present essentially 1:1 to deliver in-house day programming for the individual who remained there during the day. In addition, the residence serves individuals with significant behavioral issues. It augmented its direct care staff with a behaviorist to provide seven hours of service or consultation per week. By contrast, the other two programs retained a behaviorist for only one hour each, per week. Staffing ratios in the three programs ranged from 1:1 to 1:2.5 depending on the needs of the individual and the program shift. Most programs planned for minimal staff during weekday day-time hours from about 7 am to 3 pm when individuals were expected to be attending day activities elsewhere. Conversely, programs kept higher staffing levels on weekends when residents were present all day and might leave the residence for shopping, lunch or social or recre-

[14] Every 10th individual was selected and the program descriptions for their community facilities reviewed.
[15] Pearson correlation = .682, statistically significant at the .05 level.

ational activities. In the event that a client is sick and unable to attend their day program, staffing is provided. All programs allowed for the possibility of hiring per diem staff when circumstances warranted.

Of the 83 residents in community placements, all but two participated in some type of day activity, most often a formal day habilitation program. Day habilitation programs provide training and support for individuals with developmental disabilities to participate in activities based upon their preferences and needs, as specified in their Service Plan. Services are structured to allow for maximum self-direction and choice. Activities include, but are not limited to, vocational activities, life skills, personal development and community participation.

Table 4: Types of day programs

Day Program Types	N	%
DDD-Funded Adult Training (various types)	66	79.5%
DDD-Funded In-Home Supports	5	6.0%
State Plan Funded Medical Day Programs	10	12.0%
Nursing Home Residents	2	2.4%
Total	83	100.0%

Sixty-six individuals participated in a DDD-funded formal adult training program available outside of the residential placement setting. An additional five individuals received in-home supports; four participated in a formal day program in their residential setting, while one, who was retired, chose a less formal set of activities related to personal preferences.

Ten individuals participated in State Plan Medicaid-funded medical day programs offering "medical, nursing, social, personal care and rehabilitative services" along with lunch and transportation to and from the program.[16] One of these individuals was engaged in a senior care program.

Two individuals were engaged in activities aside provided in their nursing homes.

The Community Care Waiver provides transportation between the individual's residence and the location of their day habilitation services as a component part of habilitation service.[17] Adult Medical Day program transportation is funded through State Plan Medicaid. In addition, some medical transport for doctors' appointments, hospitals and therapies could be paid for by

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

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

the Medicaid State Plan. If the resident attends an adult medical day program, transportation must be provided by the day program.

Medical and dental care is governed by the licensing standards for residents of group homes and community care residences as set forth in New Jersey's Administrative Code. For medical care, the relevant portion of section 10:44 mandates that "Each individual shall have an annual medical examination."[18] The Administrative Code further requires that documentation of visits be maintained in the consumer's record.

Information regarding routine medical care was obtained from the DDD's Client Information System (CIS). Analysis showed that 75 individuals or about 90% had at least one medical examination following their placement.

As shown in Figure 4, following placement thirty-three individuals had one medical examination, 25 had two examinations, 14 had three examinations and three individuals had four examinations. Sixty-six individuals had documented annual medical examinations.

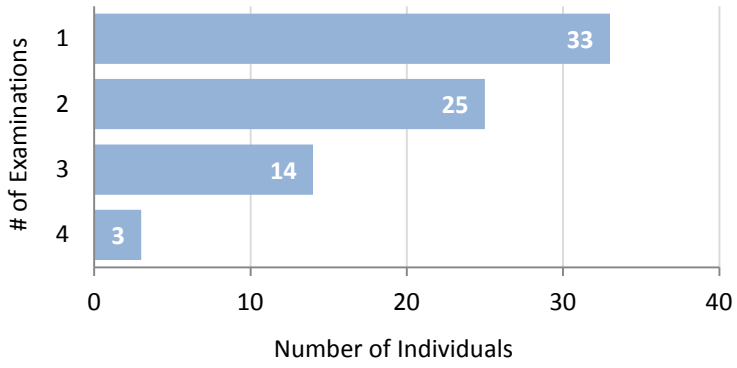

Figure 4: Number of medical examinations per individual (N=75)

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). Procedure codes associated with dental claims for oral examinations and treatment were identified by the Division of Medicaid and Health Services' Dental Director (FamilyCare) and used in the analysis. Seventy-nine individuals or more than 95% had some type of oral examination, prophylaxis or debridement following placement.

Four residents received no dental care through January 7, 2016, in two cases because the resident passed away and in a third case because the residents' seizures made dental treatment medically unsafe. The fourth individual received dental care fourteen months following placement (but outside of the window for this study). Sixty-eight residents received dental examinations or treatment on an annual basis. Sixteen residents had examinations on a more frequent basis, for example, approximately every three to six months. Barriers to complete annual ex-

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

aminations appear to be behaviors that necessitated sedation, which, in at least two cases, required clearances due to medical conditions. These circumstances delayed some dental work beyond January 2016.

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. Staff members often act out of an abundance of caution and contact 9-1-1, regardless of the particulars, because they face a $5,000 fine when a "covered" incident is not reported and may not feel equipped to judge the severity of the event. Thus, even minor cuts or scrapes may generate 9-1-1 calls.

Fifty-eight residents, or 68.9% of the 83 placed, had one or more incidents that triggered a 9-1-1 call in compliance with Danielle's Law. Nearly all (97%) of the incidents reflected medical issues, while only 1 was *exclusively* behavioral. The total number of Danielle's Law-coded incidents was 337.

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.[21] Of the 83 residents receiving community placements, 62, or 74.7%, had emergency room visits. The number of visits ranged from 1 to more than 15, with a median of 3.[22] The most common reason given for the emergency room visit was epilepsy/convulsions. It is important to note that Danielle's Law elevates ER

Table 5: ER visits post-placement

# of ER visits	N	Percentage
0	21	25.3%
1	20	24.1%
2	7	8.4%
3	9	10.8%
4	7	8.4%
5-6	7	8.4%
8-10	8	9.6%
11-12	4	4.8%
15+	3	3.6%
Total	83	100%

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

[21] Only emergency visits occurring after community placement were considered. Emergency room visits were based upon the resident having an outpatient hospitalization with a review code for a type of emergency room visit. In order to avoid duplicate records for the same visit, the analysis also selected residents with procedure codes specifically associated with the emergency room visit rather than other billing codes occurring on the same date. These duplicate records were for the following types of procedures: catheter insertion, arm or leg splits, IV, injections or immunizations, feeding tubes, wound repair, overnight monitoring and diagnosis.

[22] Note that the median rather than the average is used because of the substantial spread and the presence of an extreme outlier (N=44 visits) which skews the average. The median means that half of the residents had more than 3 visits and half had fewer than 3 visits.

visits as a consequence of mandated 9-1-1 calls.

Of the 83 Woodbridge residents moved to the community, 28 or 33.7% had one or more hospitalizations for medical conditions, with epilepsy the most common reason cited.

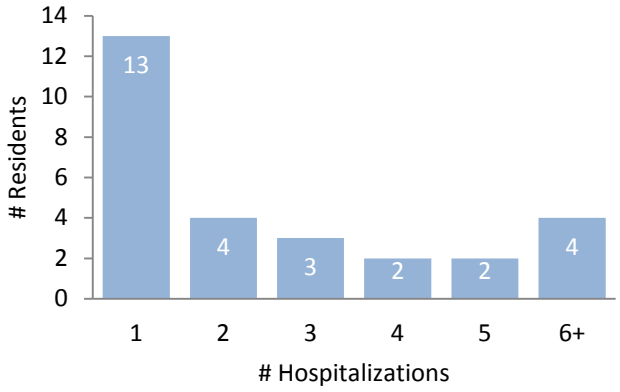

Figure 5: Number of hospitalizations following placement

Table 6: Top reasons for hospitalizations

Reason	N
Epilepsy	26
Blood	18
Respiratory	17
Gastrointestinal	9
Swallowing	9

Outcomes

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

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

The tool used to assess individuals' functioning was developed by the Developmental Disabilities Planning Institute (DDPI), created in the mid-1990's as a university-based research organization and currently situated within Rutgers University. The New Jersey Comprehensive Assessment Tool (NJ CAT) is used annually to assess the placement cohort regardless of their residential setting.[23]

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

The information reported here is the baseline score post-placement and compares scores for individuals placed in the community and those placed in other DCs. Data were available for 77 of the 83 community residents and 205 of the 236 DC placements. These scores will be compared to subsequent annual assessments to determine changes in functioning for both populations over the five-year period.

To summarize the results, in the case of cognition, basic self-care, and mobility, differences were not statistically significant.

The cognition scale consisted of 20 items (See appendix).[24] Responses were either "yes" or "no." Scores could range from "0" for individuals who were unable to complete any of the tasks to a maximum of 20 if individuals could perform all tasks. Items pertained to memory,

[23] 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.

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

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 .81 and for the DC residents was 1.17. A statistical analysis shows that these differences were not statistically significant.[25]

The basic self-care need scale consisted of 14 items (See appendix). 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. According to Rutgers' researchers, summary scores of less than 34 indicated a substantial limitation while scores above 34 indicated no substantial limitation. A statistical analysis of the data shown in Table 7 found that these differences were not statistically significant.[26]

Table 7: Basic self-care total scores by residence type

Scores	Community	DC
0	62.3%	61.5%
1	23.4%	20.5%
2	6.5%	6.8%
3-10	7.8%	9.3%
11+	0.0%	2.0%

A single question captured mobility: *"Does (name) walk independently without difficulty, without using a corrective device, and/or without receiving assistance."* Analysis shows 16.9% of the community residents and 20.5% of the DC residents were able to walk independently. Again, these differences were not statistically significant.

Table 8: Limitation in self-care by type of residence

Limitation	Community	DC
No substantial limitation	1.3%	5.9%
Substantial limitation	98.7%	94.1%

Are community residents satisfied with their residential placements – or would they prefer to live in a developmental center? Many residents had significant cognitive impairment and could not be interviewed.[27] Decisions regarding placement were made and approved by teams and

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

[26] Using Pearson's chi-square.

[27] The researchers utilized information from the most recent NJ CAT (Comprehensive Assessment Tool) to determine the likelihood that former residents could make a comparison and were able to recollect past experiences. Three items were utilized for this purpose: whether former residents knew the difference between shapes,

families. Of the community residents who could be interviewed about their housing preferences[28], two of the three community residents expressed a strong preference for where they were living now though their reasons for this preference varied. One resident appreciated the privacy and choice available, saying "I like the house. I can do anything. I can sleep. I can watch TV…I like my staff. My staff do not bother me." The other resident said (about Woodbridge) "I don't want to be stuck over there." In regard to the group home, this individual said, "I like living here. I am not going anywhere else." When asked what accounted for his preference, the resident indicated that he did not like loud noises, and with regard to where he lived now, he said "It is peaceful." The third resident did not like Woodbridge, but also did not like the current group home. This individual stated a preference to be moved to another group home. When given the choice of another group home or Woodbridge, the resident indicated a preference for another group home, "A group home is better for me."

Information about contacts residents have with family was obtained from a survey of case managers regarding the type and frequency of family contact for each resident. The results show that 19 of the 83 placed in the community had no family. Of the remaining 64 with family, 50 had at least annual contact. Of the 50: 16 had at least weekly contact; 13 had at least monthly contact; 21 had at least annual contact.[29] Seventy-nine community residents or 96.3% had access to peers, primarily on a daily basis.

Table 9: Family involvement among community residents

Family involvement	N	%
Family involved	64	77.1%
No family	19	22.9%

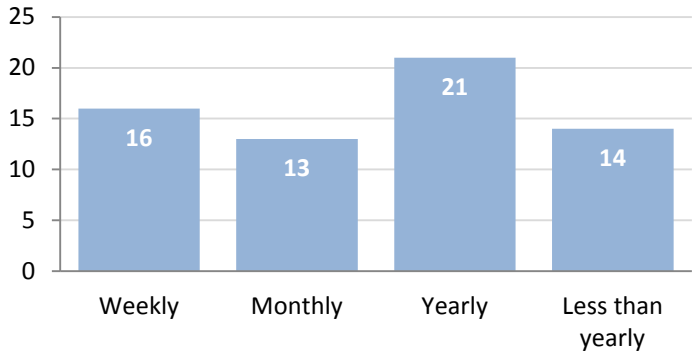

Figure 6: Frequency of family contact (N=64)

whether they were able to remember events that happened a month or more ago, and whether the residents were able to understand a joke or story.

[28] Four were determined eligible to be interviewed based on the NJCAT information. One of the four was unable to participate; results are based upon in-depth interviews with three community residents. The same DHS staff person interviewed each of these residents, either at the consumer's residence (N=1) or day program (N=2). The residents were asked what they liked and disliked about their lives at Woodbridge and where they were living now, and where they would prefer to live if given the choice.

[29] Findings from the survey were reinforced by analysis of records from the Alternate Living Arrangement (ALA) form. The form documents family contact by either the month or quarter. The ALA data were available for 82 of the 83 residents placed in the community. Documentation shows that 59 residents had some contact with family post-placement, closely approximating the 64 that according to case managers have family.

The study also incorporated the perspectives of private guardians about the Woodbridge cohort's quality of life. A survey[30] was mailed to the family/guardians of the 50 individuals who had been placed in the community and had private guardians (i.e., family members, friends, or advocates). Of these 50 individuals, there was contact information available for one or more relatives or guardians of 43 residents. Family/guardians who did not respond to the initial mailing received a postcard reminder followed by up to three phone calls.

As of October 14, 2016, family/guardians of 31 former Woodbridge residents had responded to the survey, a response rate of 72.1%.[31] Twenty-eight respondents (90.3%) were related to the former Woodbridge resident, while three were private guardians (9.7%). Relatives were primarily either siblings (41.9%) or parents (38.7%). Other family members included an aunt or uncle, a niece or nephew and a cousin (9.6% combined).

Nearly all (90.3%) of the respondents (N=28) had visited former Woodbridge residents in their community placements. Only one respondent had no contact, direct or indirect, with the individual placed. Seven respondents contacted staff at the residence. Four 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, four individuals both visited and had contact via phone or email. Of the seven that contacted staff, four also visited the residence.

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

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

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

[31] Of the twelve that have yet to respond, six were contacted by phone and per their request were sent a new survey either by mail or email, but did not complete the survey during the subsequent month. Family/guardians of the other six individuals could not be reached.

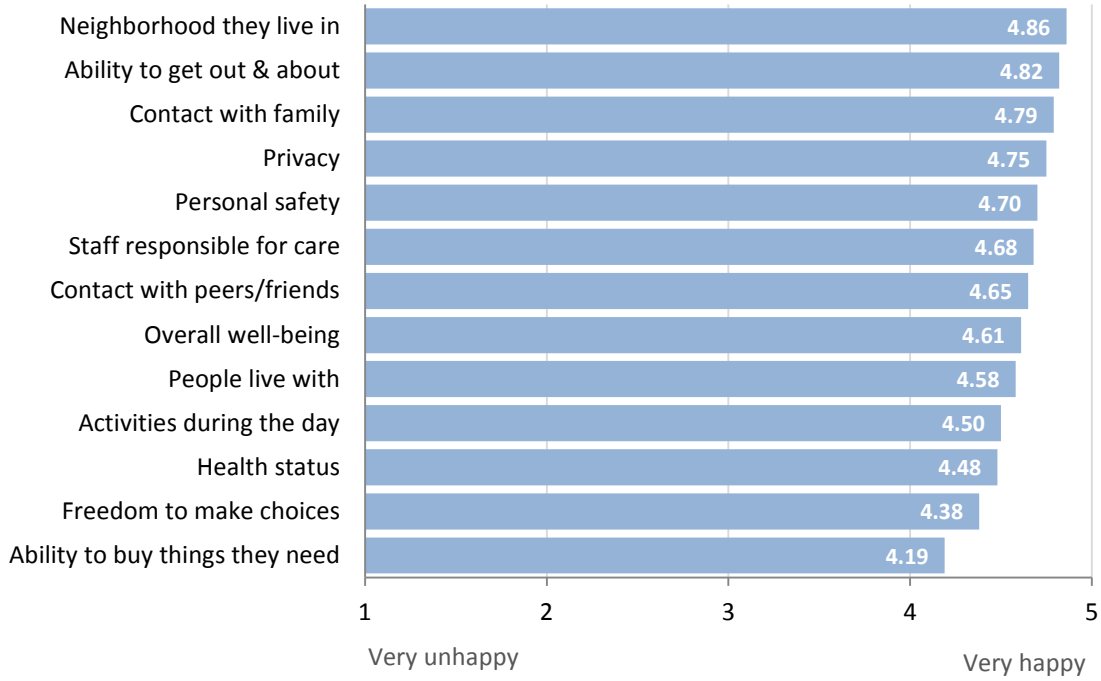

Figure 7: Average rating of family guardians' happiness with consumers' living situations

Average scores for each of the 13 items exceeds a 4 with most items falling between 4.5 and 5.0 (indicative of being "very happy").[32]

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

High reported satisfaction was evident in the item averages, which ranged from a low of 4.56 to a high of 4.80, where a "5" indicates the respondent is "very satisfied." The rating for average satisfaction with a day program or work activity at 4.8 was the highest for any of the community programming ratings.

[32] The legislation specifically mentions personal safety and health status, both of which are rated over 4.5.

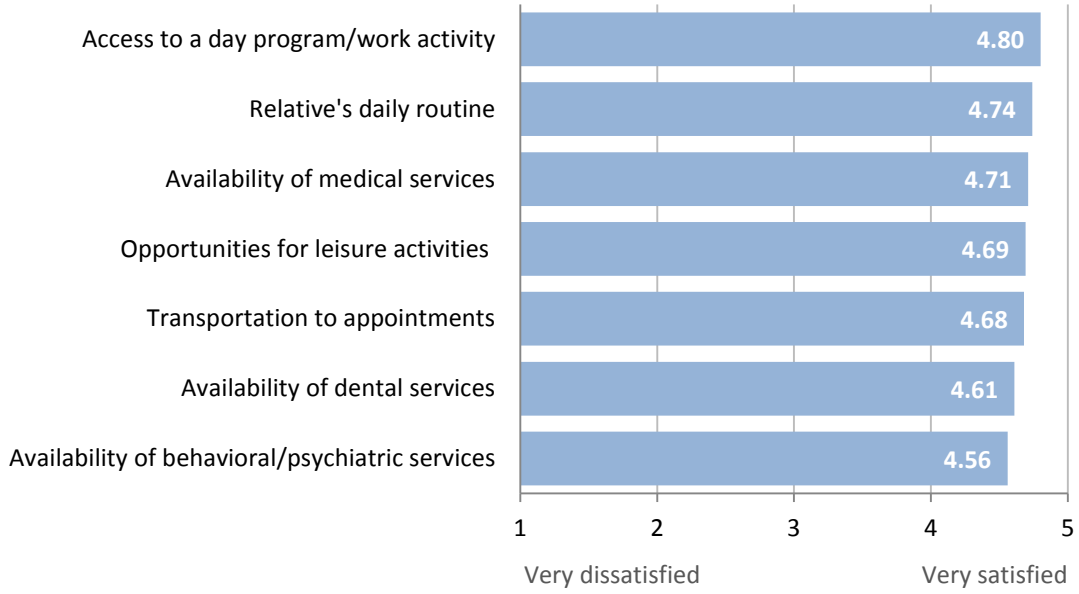

Figure 8: Average ratings of programming and services (higher scores indicate greater satisfaction)

A comparison was made to how private guardians for the Woodbridge residents transferred to other developmental centers perceived quality of life in these DCs. Surveys were sent to 155 family/guardians with contact information.[33] As of January 6, 2017 surveys had been received from 83 family/guardians. These included two residents with two family respondents each; one survey each was chosen at random, leaving 81 surveys and a response rate of 51.9%. All of the respondents were family members, primarily siblings (51.9%) or parents (39.5%).

Table 10: Guardian Perception of Relative's Well-being

How relative is doing overall	Community (n=31)	DC (n=81)
Excellent/Good	80.6%	82.7%
Fair/Poor	13.0%	9.8%
Don't know/missing	6.4%	7.4%

Note: 13% equates to 4 people and 9.8% equates to 8 people.

Comparisons between 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 satisfaction with community programming. The results showed that in virtually all domains average ratings of qualify of life and program satisfaction may have been slightly higher for community residents. However, with two exceptions, none of the results was statistically significant. The ex-

[33] Each person who did not respond to the initial mailing received a postcard reminder followed by at least three phone calls.

ceptions were the residents' ability to get out and get around and the residents' access to either a day program or work activity. Family/guardians of community residents were significantly more likely to feel that their relatives could get out and about and had access to a day program or work activity.

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

The measure of the need for medical supports considers three levels of medical need for assistance. [34] As shown Figure 7, both populations predominantly need specialized medical care, but compared to the community residents, a greater percentage of DC residents need the more intensive specialized on-site nursing care.

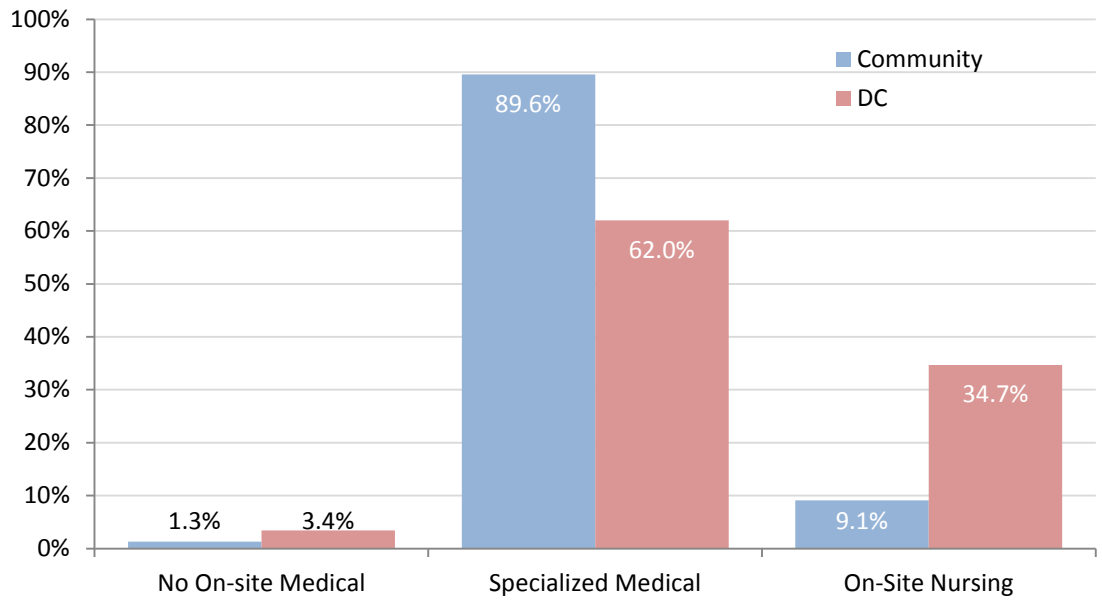

Figure 9: Medical assistance by residential placement type

[34] 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.

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

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

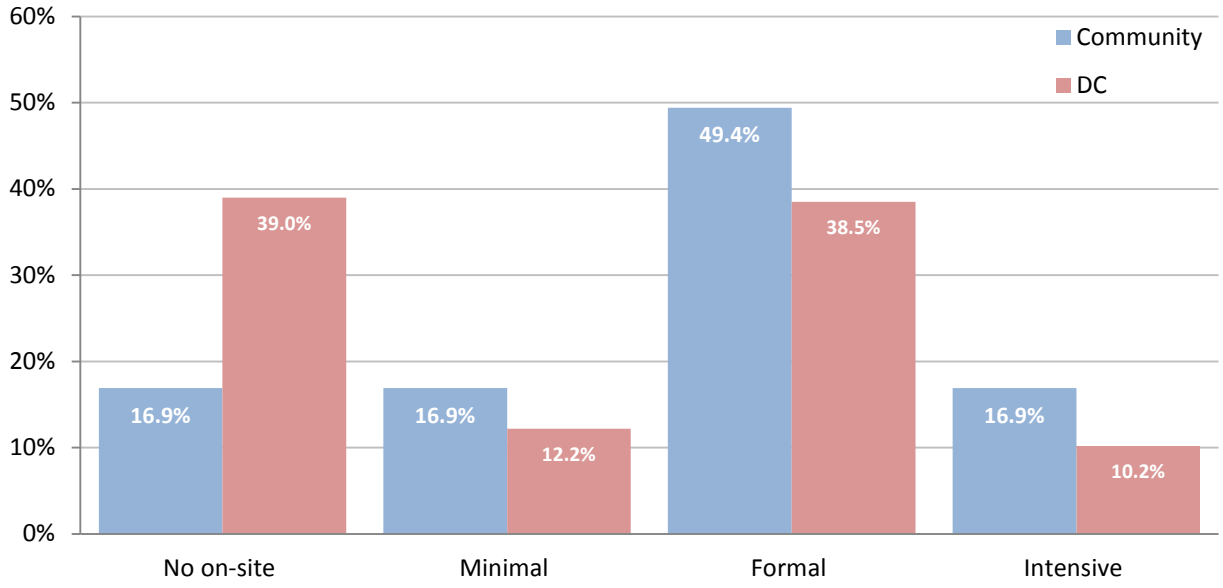

Figure 10: Need for behavioral supports

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

Of this cohort of 333 Woodbridge Developmental Center residents, thirty-six, or 10.8%, passed away. Ten of them, or 3%, passed away in the developmental center prior to placement. Twenty-six residents, or 7.8%, passed away following placement as follows: 20 after placement in developmental centers, 4 following placement in the community, and 2 following placement in skilled nursing facilities. There were an additional two residents discharged to family out-of-state whose outcomes were unknown.

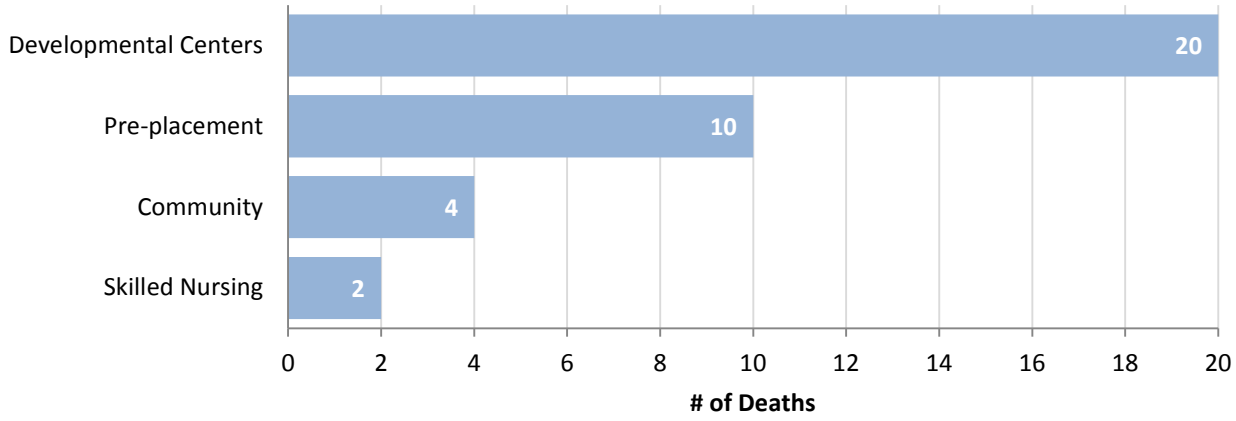

Figure 11 Number of deaths by placement type

The researchers used a cut-off of six months to look in detail at the cases in which the death occurred in close proximity to the move. There were a total of five deaths of the 26 that occurred within six months of placement. All had significant medical issues, such as difficulty swallowing (dysphagia) and cancer; one was in hospice and one died of complications from the flu despite being given the vaccine.

The Department of Human Services' Unusual Incident Reporting and Management System (UIRMS) captures information on a range of unusual incidents including operational (e.g., a minor fire extinguished by staff), operational breakdowns (when an outage or disruption poses a threat to health and safety and/or impacts facility operations), unexpected staff shortages (if the shortage results in the inability to safely evacuate residents or if appropriate levels of supervision cannot be maintained), criminal activity, or media interest around a reportable incident. Regulations stipulate that criminal activity involving individuals served or staff "is reportable when the event constitutes a crime in accordance with NJ criminal statutes and police take a report or file charges." Entries in the UIRMS database include the incident code, date of the incident, the responding party, and the action taken however, there is often a lack of clarity and standardization in the documentation of law enforcement involvement. This is largely because the criminal justice system is not obligated to provide the Division with updates on its work. Therefore, incident codes were augmented by a review of the incident narratives, which resulted in eleven incident reports through January 7, 2016, but no evidence of criminal charges.

The incidents involved loss or theft of controlled substances, vehicular accidents without injury, instances where residents threatened staff, destroyed property, or acted out, with the police primarily performing peace-keeping functions and one instance of inappropriate use of restraints with minor injuries.

Appendix A: Medical and Behavioral Supports Levels Table

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

Medical Supports

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

Behavioral Supports

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

Self Care Support Needs

DDD Individualized Resource Tool

Level 1 to 4

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

Level I

Lowest Support Time Needed, Highest Self Care Score

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

Level II

Low Support Time Needed, Medium Self Care Score

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

Level III

Medium Support Time Needed, Low Self Care Score

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

Level IV

High Support Time Needed, Lowest Self Care Score

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

Appendix B: Family Guardian Survey

1. INTRODUCTION

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

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

Please return your completed survey by August 5, 2016 in the stamped, addressed envelope provided. If another member of your household receives a survey, they should complete and submit their own survey.

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

If you have any questions, please contact Patricia Guyton at (609) 292-8155.

Thank you for your participation!

Family and Guardian Survey

2. SURVEY

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

Your Name (Print):

Initial of *Consumer's* First Name (e.g., "M" for Mary):

2. How are you related to the consumer affected by the closure of Woodbridge Developmental Center? (Select ONE)

- ○ Mother/Father
- ○ Aunt/Uncle
- ○ Brother/Sister
- ○ Niece/Nephew
- ○ Other (please specify)

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

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

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

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

5. How would you rate their current residence? (Select ONE)

- ○ Very attractive - unique and attractive design, excellent maintenance
- ○ Somewhat attractive - may show some deterioration on close inspection, or design is adequate but not unusually attractive
- ○ Ordinary - building is somewhat attractive but poorly maintained or is not notable in either design or maintenance
- ○ Unattractive - building is deteriorated or unattractive
- ○ Don't know

6. How would you rate the public spaces in their current residence such as the living room, dining room and/or kitchen in terms of clutter and neatness? (Select ONE)

- ◯ Neat - living spaces are very orderly; there seems to be a "place for everything and everything in its place"
- ◯ Some disarray - looks "lived in"; some furniture moved around, magazines lying around, etc.
- ◯ Cluttered - living spaces are somewhat disorganized and messy; some objects lying about; area seems crowded
- ◯ Very cluttered - furniture and other objects are in disarray; floor area has objects to maneuver about.
- ◯ Don't know

7. How would you rate the condition of the furniture in their current residence? (Select ONE)

- ◯ Excellent condition - like new; well-kept, spotless, highly polished or without stains
- ◯ Good condition - not new, but in good condition, slightly worn, small scratches, dusty, a few stains, some dirt in creases.
- ◯ Fair condition - older, but still structurally sound; moderately clean.
- ◯ Deteriorated - old and in poor repair; some tears, stains, dirt or dust; may be structurally unsound or dangerous.
- ◯ Don't know

8. Have you noticed odors in their current residence? (Select ONE)

- ◯ No odors - nothing noticeable about the air; "normal"
- ◯ Slightly objectionable - air is slightly tainted in some way' stale, close, musty, medicinal
- ◯ Distinctly objectionable - unpleasant odors are apparent
- ◯ Don't know

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

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

Other (please specify)

10. 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	◯	◯	◯	◯	◯	◯

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

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

12. 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.

13. Do you have any additional comments?

- ◯ Yes
- ◯ No

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