NYS Office of Mental Retardation & Developmental Disabilities

Putting People First

National Core Indicators New York State Report 2007-2008

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The National Core Indicators New York State Report is a product of the Division of Policy and Enterprise Solutions (DPES). DPES provides project development, enterprise services, and advisement to OMRDD's senior management and to the voluntary sector, focused on five areas: policy analysis, strategic planning, service design and innovation, program research, and clinical and behavioral health.

In addition, special thanks to the Division of Quality Management and the Developmental Disabilities Services Offices who facilitated data collection across the state. This report was made possible through the collaborative efforts of staff throughout OMRDD.

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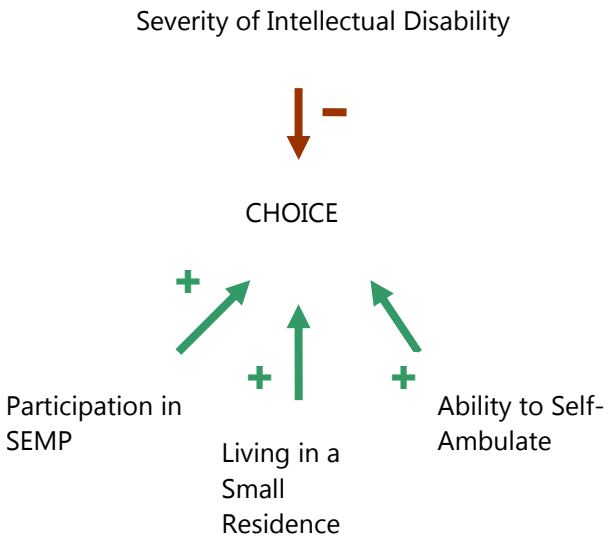
Executive Summary

The National Core Indicators (NCI) project began in 1997 as a partnership between the Human Services Research Institute (HSRI), the National Association of State Directors of Developmental Disability Services (NASDDDS), and state developmental disability agencies. The purpose of the project is to develop indicators to measure the performance of state developmental disability systems. In 2007, the New York State Office of Mental Retardation and Developmental Disabilities (OMRDD) joined the project to enhance the agency's quality management activities and performance metrics. This report examines findings from the 2007/2008 Consumer Survey and offers policy recommendations for areas where OMRDD has an opportunity to demonstrate significant improvement.

This report focuses on four people first goals – home, relationships and inclusion, health, and productivity. Additionally, results on three cross cutting areas – choice, individualization and information and planning are also presented. The results of the analysis suggest several characteristics of the person and of services that are positively or negatively associated with the different goals of our service system. Choice is one of the areas where predictors that explain variation could be identified. The diagram below shows the factors that are associated with different levels of choice and are more thoroughly discussed in subsequent sections of this report.

Factors That Predict Choice Scores



The four characteristics contained within the diagram can explain over 40% of the variation in choice scores. Choice is one area where there is ample opportunity to improve. In general, individuals we serve report having little choice over the home they live in, the people they live with, staff they work with and day activities they participate in.

There is also evidence that the extent of community inclusion and belonging are linked to some of the same factors mentioned above. Although a strong model that predicts variation in the community inclusion scale score could not be found, there is some evidence that people who self-ambulate, participate in SEMP and experience less severe intellectual disabilities enjoy greater community inclusion.

Regarding our "People First" goals, it is clear that NYS performs competitively with other states in the areas of home, health, work and relationships. However, there is still room for improvement. For many indicators our goal should be a 100% positive response rate. The following table presents weaknesses in our system, identified through survey results and organized by our "People First" areas.

Weaknesses in "People First" Areas			
Home	**Relationships**	**Health**	**Productivity**
Safety	Quality of social networks	Exercise	Opportunities to work
Privacy	Reciprocity of relationships	Diet	Opportunities to learn
			Ability to retire

Concerning the home domain, nearly twenty percent of respondents did not feel completely safe in their homes and/or neighborhoods. Between fifteen and twenty percent of respondents reported that people enter their bedrooms and homes without permission. The responses to survey items related to relationships suggest that relationships may not be reciprocal. Only 68.3% of people reported that their friends get in touch with them and only 56% of people reported that their friends ask them to do things. Arguably, these percentages should be closer to 100.
There is also room for improvement in the number of people reporting that they have friends they like to talk to or do things with since only three quarters of people giving a positive response to this survey item. In the area of health, people with developmental disabilities struggle with getting enough exercise and keeping a healthy weight. The percentage of women receiving gynecological exams and percentage of people receiving dental exams within the last year and six months, respectively, should be examined to ensure that individuals we serve are abiding by best practices. Lastly, in the domain of work and productivity, fewer than 30% of those surveyed felt they had a chance to earn good money, work as many hours as they want or retire if they are of retirement age.

Recommendations that address many of these weaknesses are in blue text throughout this report. A variety of actions will be required to address all weaknesses; staff training may improve performance in some areas while other areas of weakness may require a greater commitment of resources. Overall, the results of NCI show that people are satisfied with many aspects of OMRDD's service system and their lives. Most individuals are happy with their home and day activities, have someone they consider to be a best friend and experience good health. This report has identified areas where improvement is needed and identified predictors of choice and groups that are at risk for reduced community participation. With this new knowledge, OMRDD can continue to make strategic decisions that move our system towards improved performance.

Section 1 - Introduction

National Core Indicators Project

The National Core Indicators (NCI) project began in 1997 as a partnership between the Human Services Research Institute (HSRI), the National Association of State Directors of Developmental Disability Services (NASDDDS), and state developmental disability agencies. The purpose of the project is to develop indicators to measure the performance of state developmental disability systems. The current set of indicators assesses outcomes in the following domains:

- Consumer Outcomes
- Family Outcomes
- Case Management
- Incidents
- Mortality
- Staff Stability
- Board Composition

As of July 2009, 30 states participate in NCI, each utilizing the data for various purposes. Many states adopt NCI as one facet of their Quality Management process, for example. HSRI provides states with training materials, instruments and protocols to facilitate data collection. Participating states implement data collection activities until they reach their target sample size and then submit their data to HSRI. All of the states' data are compiled by HSRI and summarized in various reports that compare results among states.

OMRDD Participation

In 2007, the New York State Office of Mental Retardation and Developmental Disabilities (OMRDD) joined the project to enhance the agency's quality management activities and performance metrics. As an organization, OMRDD excels in corporate compliance and regulatory controls. However, there is a need to assess outcomes important to individuals and family members at the systems level. With the development of a new mission and vision statement emphasizing "Putting People First" and the implementation of the OMRDD strategic framework focusing on home, health, productivity, and relationships, NCI was a natural fit for assessing the organization's success in supporting individuals with developmental disabilities. OMRDD will continue to participate in the project annually to monitor performance and address areas that need improvement.

This report examines findings from the 2007/2008 Consumer Survey and offers policy recommendations for areas where OMRDD has an opportunity to demonstrate significant improvement. The analysis compares the performance of NYS to the national average for indicators reflecting each of the "people first" areas as well as other areas of importance. Performance on scales developed by HSRI (choice and community inclusion scales) as well as scales developed by OMRDD (individualized services and person-centeredness scales) is examined. Lastly, predictor variables that explain variation in scale scores were identified.

Section 2 - Methods

Participants

Two groups of individuals were sampled for participation in the Consumer Survey. The first group, called the "main sample" represented all services traditionally offered by OMRDD. The second sample, called the "OPTS (Options for People through Service) sample," represented people receiving services provided through NYS OPTS contracts. The goals of different OPTS projects varied but were primarily related to improving the quality of services provided to individuals and improving outcomes in areas such as community integration and skill acquisition.

Participants in the main sample were selected randomly, stratified by service type and geographic region. OMRDD services were categorized into three major types: residential, day, and individual. The residential category included individuals receiving residential services at certified sites. The day category included individuals receiving day services, who did not reside in certified sites. The individualized services category included individuals receiving family support services, individual support services (ISS), and/or consolidated supports and services (CSS), and not receiving certified residential or day services. Individuals who only received Medicaid Service Coordination were excluded from participation. Each region of NYS had a target for the number of participants to interview based upon the total population of people receiving services in that area. Utilizing this methodology, a sample of 464 individuals was interviewed for the main sample.

The OPTS sample included 246 individuals receiving services through NYS OPTS contracts. Similar to the main sample, participants were randomly selected and stratified by service category and geographic region.

Participation in the Consumer Survey was voluntary, and each person and/or his or her advocate/guardian made their own decision to participate. To account for refusals, interviewers were given a list of several names and were instructed to choose the next person on that list, should the first person refuse to participate.

Data Collection

Interviewers administering the Consumer Survey included OMRDD staff from both the Developmental Disability Services Offices (DDSO) and the Quality Management (QM) Field Offices. DDSO and QM staff members have extensive experience working and interacting with individuals with developmental disabilities. To prevent bias, no one providing a direct service (service coordination, habilitation, personal care, etc) or supervising staff providing a direct service could interview the participants. Interviewers attended a one day training session conducted by OMRDD and the Human Services Research Institute (HSRI) to ensure consistency and proficiency in administering the instrument. Medicaid Service Coordinators provided demographic and contact information on each individual to assist interviewers in scheduling and facilitating the interview. Interviews began in 3/08 and ended in 6/08.

Instrumentation

The Consumer Survey is an opened ended, standardized survey, measuring indicators related to quality of life and consumer satisfaction. The Consumer Survey was developed in 1997 by HSRI and has been used by at least 30 different states to interview individuals with developmental disabilities. The psychometric properties of the instrument were established through test and retest reliability and face validity via an expert panel. Based upon interviewer feedback, the survey is modified and field tested to ensure validity and reliability. Interviewers are trained to first ask questions as written, but also have the ability to paraphrase questions in order to obtain valid responses. The interview is open ended and the interviewer is expected to interpret the response of the individual and code the response into the response category that best matches the person's answer.

The survey includes domains measuring home, health, work, community inclusion, friends and family, rights and privacy, and satisfaction with services. The first section of the survey consists of questions that can only be answered by individuals

receiving services since these questions are primarily concerned with the thoughts and feelings of the person. The second section of the survey is composed of items that focus on factual information, such as whether the person goes out to eat or goes shopping. These items may be answered by a proxy, which is considered an acceptable practice when individuals with developmental disabilities are not capable of answering. (McVilly, Burton-Smith, Davidson, 2000) This protocol allows states to include participants of all different ability levels, not just those who are able to participate independently.

Section 3 - Results

Demographics

The NCI main sample was representative of the individuals served by NYS OMRDD. For each of the three tables below, the percentages reflecting the NCI sample can be found on the right hand sides of the tables. The numbers reflecting the OMRDD system, as a whole, are found under the "population" heading in the table, where both the frequency (raw number) and percentages are presented. Note that the population reflects individuals receiving residential, day or individualized services who are 18 years of age or older.

Ethnicity

Table 1.

	Population		**NCI Sample**
ETHNICITY	Frequency	Percent	Percent
White	48,503	65.6	71.7
Black/African American	14,636	19.8	17.8
Hispanic	8399	11.4	9.5*
Asian or Pacific Islander	1190	1.6	.2
American Indian/Alaska Native	234	.3	0
Other	943	1.3	10**
Missing	3187		
Total***	77,092	100	100

HSRI reported statistics on the ethnicity of those included in the NYS NCI sample, shown in the right hand column of table 1. The percentage of each ethnicity in the NCI sample can be compared to the overall population of adults receiving residential, day or individualized services through OMRDD. Overall, each ethnic group seems adequately represented.

* Hispanic is defined as an ethnicity in the Consumer Survey – a separate survey item exists for race. The NYS Developmental Disability Profile (DDP) groups "Hispanic" along with other races. Therefore, the comparison of the percentages of Hispanics across the NCI sample and the population should be done with care.

** The "Other" category in this table is composed of individuals who choose the following responses in the NCI survey:" Other race not listed", "two or more races" and "don't know".

*** Included in the "Total" calculation are the 3178 individuals with missing data.

Severity of Intellectual Disability (ID)

Table 2.

	Population		NCI Sample
	Frequency	Percent	Percent
LEVEL OF INTELLECTUAL DISABILITY			
Normal	1872	3.0	5.0
Mild	23,283	37.4	35.6
Moderate	16,256	26.1	22.8
Severe	8791	14.1	13.1
Profound	10,271	16.5	21.8
Not Determined	1802	2.9	1.7*
Missing	14,818		
Total	77,092	100	100

*Percent with a "don't know" response

Table 2 (left) shows that all levels of intellectual disabilities were represented in the NCI sample in a way that reflects the population. An "ID score" was created in order to test whether the surveys completed reflected levels of intellectual disability in the population. People with No ID were coded as a 0, Mild ID = 1, Moderate ID = 2, Severe ID = 3 and Profound ID = 4. The average ID score for the population was 2.04 and the average for the NCI sample was 2.12. These scores were not significantly different.

Other Disabilities

Table 3.

	Population		NCI Sample
	Frequency	Percent	Percent
OTHER DISABILITIES			
Autism	8934	11.6	8.0
Cerebral Palsy	9908	11.1	16.6
Psychiatric Diagnosis	24,299	36.7	26.1
Hearing and/or vision problem	25,062	40.1	23.1

Table 3 (left) suggests that individuals with a psychiatric diagnosis or with hearing and vision problems are underrepresented in the NCI survey by over 10 percentage points. The percentage of individuals with autism and cerebral palsy in the NCI sample more closely reflect the population. Only individuals with a completed Developmental Disabilities Profile (DDP2) record listing the particular disability are included in the population frequencies and percentages. The Autism percentage is calculated using the full population of interest as the denominator (77,092). The denominator used to calculate the population percentage differs across disability type because of variation in the number of people with information on that particular disability.

Gender

Table 4.

	Population		NCI Sample
GENDER	Frequency	Percent	Percent
Female	32730	42.5	40
Male	44362	57.5	60

The gender breakdown was compared between the NCI sample and the adult population served by OMRDD. Table 4 (left) shows that the NCI sample reflected the breakdown existing in the population.

Age

Table. 5

	Population	NCI Sample
DESCRIPTIVE STATS		
Minimum	18	18
Maximum	108	93
Mean	40.6	45.26
Std. Deviation	15.43	14.85

Table 5 suggests that the average age of individuals included in the NCI sample was roughly equivalent to individuals in our service system.

Synopsis of Demographic Analysis

All of the information presented above supports the argument that the NCI sample adequately reflects the demographics of the individuals we serve. However, there was some level of under-representation for people with psychiatric diagnoses and people with vision and/or hearing impairments.

Recommendations

- OMRDD will continue to draw the sample for the Consumer Survey in a way that represents people with developmental disabilities but may consider over-sampling certain groups if trends in under-representation continue.

- These results should be shared with staff administering the survey to explore reasons for under-representation of individuals with mental health diagnoses, vision impairments, and hearing impairments.

Summary of New York State Results

The full HSRI Consumer Outcomes Final Report for the 2007-2008 data can be accessed through the following url: http://www.hsri.org/docs/CS%2007-08%20FINAL%20REPORT.pdf. The HSRI report displays item-by-item results for all states participating in NCI. This report will summarize the results for NYS in a format that clearly identifies performance on OMRDD's "people first" areas. Some of the data is taken directly from the HSRI report. However, NYS OMRDD conducted data analysis for survey items pertaining only to NYS and performed additional inferential analysis.

As mentioned in the methods section, NYS pulled two random samples, one that only included individuals receiving traditional services (main sample) and another that included individuals receiving services through OPTS. NYS only submitted data to HSRI for the individuals included in the main sample. Therefore, all data that is reported by HSRI includes only those from the main sample. Information about the methodology used by HSRI can be found in the full report referenced above. In keeping with HSRI's methodology, in Section 1 of the survey, NY only reported results for people who understood the survey questions and gave valid responses. The analysis of Section 2 included all responses since the responses were either provided by an individual receiving services who was capable of responding or a proxy.

<u>How to Read Tables in Section 3</u>

The following tables will use both the HSRI results and results that have been generated by NYS OMRDD. The tables below use the HSRI data when performance comparisons are made between NYS and the national average. HSRI adjusted the data to control for differences in the population served by each state, which allow for appropriate state to state comparisons. Each table has a "comparison column" containing a green, blue or red circle. Green circles (◯,●) indicate that NYS exceeded the national average while red circles (◉,○) indicate that NYS fell below the national average. **The red and green circles are used when NYS differs from the national data in a way that is statistically significant.** A blue circle (●) signifies that there is no statistically significant difference between NYS and the national average.

As mentioned in the methodology section, OMRDD pulled two different random samples – an OPTS sample and a main sample. Generally, the OPTS and main samples were combined for analyzing the NYS questions. Statistics reflecting only the main sample were reported if a statistically significant difference existed between the two samples for a particular item. There are only two survey items where this is the case and they are identified in the results section of this report.

Home

Indicators of Satisfaction with HOME LIFE

OMRDD is committed to assisting individuals with developmental disabilities to live in the home of their choice. NCI home indicators measure concepts related to satisfaction, choice, rights, and safety within the person's home.

% All numbers are percentages %

National comparison data are from the 2007-2008 NCI collection year. The last question was created by NYS, so no national comparison data exist. All state-to-state comparisons use adjusted HSRI data, except where otherwise noted.

Legend for Comparison column:	○	◉	●	○	●
	5 points or more below national average	**Up to 5 points below national average**	**No statistical difference from national average**	**Up to 5 points above national average**	**5 or more points above national average**
	○	◉	●	○	●

	Yes		
	NYS	**Nat'l**	**Comparison**
Do you like where you live?	92.1	94.7	●
Can you be alone when you want to?	91.5	91.3	●
Do you feel safe in your home?	82.2	83.0	●
Do you feel safe in your neighborhood?	79.7	83.1	●
Is the staff respectful?	92.9	88.7	●
Do people enter your home without permission? *Note: lower percentages are better	15.2	14.3	◉
Do people enter your bedroom without permission? *Note: lower percentages are better	19.1	19.6	○

Note: The following is a NYS question; no national data exist.	**Yes**
Do you usually get along with people you live with?	94.1

Synopsis of Home Life Analysis

Home Life is an area where NYS, along with many other states, performs well. NYS performs within the average range or better for all items except the item that addresses entering the home without permission.

Recommendations

- Respect for the privacy of individuals we serve must be emphasized through staff training upon entrance to the workforce and continuing education for current support staff.

Privacy and rights are important issues for individuals with developmental disabilities, especially when concerning one's home. OMRDD will work with state and voluntary providers to ensure that staff and visitors understand that a house or apartment is first and foremost a person's private home, not a program.

- OMRDD must work to increase feelings of safety through increased choice in home selection and strive to increase community acceptance and neighbor involvement.

The results of the survey show that the performance of NYS is comparable to the national average for safety items, but that is not a reason to be complacent. There is room for improvement since nearly twenty percent of individuals surveyed reported not feeling fully safe in their homes and neighborhoods. At this time OMRDD continues to encourage home-ownership for individuals with disabilities and their caregivers. As more people are empowered to choose the location of their home, indictors of safety will be closely monitored to track whether improvement occurs.

Relationships and Community Inclusion

One of OMRDD's goals is to support people with developmental disabilities to have meaningful relationships with friends, family, and others of their choice. The NCI base survey includes five items in the friends and family sub-domain. NYS OMRDD added four questions targeting quality of relationships to better assess the extent to which people have relationships in their communities.

Relationships
Indicators of QUALITY RELATIONSHIPS

% All numbers are percentages %

National comparison data are from the 2007-2008 NCI collection year. The questions in the last table were created by NYS, so no national comparison data exist. All state-to-state comparisons use adjusted HSRI data, except where otherwise noted.

Legend for Comparison column:	○	◉	●	○	●
	5 points or more below national average	Up to 5 points below national average	No statistical difference from national average	Up to 5 points above national average	5 or more points above national average
	○	◉	●	○	●

	Yes		
	NYS	Nat'l	Comparison
Do you have a best friend or someone you are really close to?	84.5	85.2	●
Do you have friends you like to talk to or do things with?	74.3	70.6	●
Can you see your friends when you want to see them?	77.4	79.8	●
Do you ever feel lonely? *Note: lower percentages are better	38.2	45.5	●
Can you see your family when you want to?	74.8	77.5	●

Note: The following are NYS questions; no national comparison data exist.	**Yes**
Do your friends get in touch with you?	68.3
Do your friends ask you to do things with them?	56.1
Have you gone on a date in the last six months?	30.9
Do you have someone to talk to when something bothers you?*	90.4

* This percentage reflects the main sample only because the main and opts samples had a statistically significant difference in the percentage of people who responded "yes" to this question.

COMMUNITY INCLUSION

A community inclusion scale was developed by HSRI consisting of seven questions pertaining to whether individuals participate in everyday integrated activities in their communities. Middling scores on this scale are not necessarily a cause for concern given that people may actively choose not to participate in the community activities that would increase scale scores (such as going to religious services or playing integrated sports). It would be more concerning if NYS performed much worse than other states – this is not the case.

Indicators of COMMUNITY INCLUSION

% All numbers are percentages %

National comparison data are from the 2007-2008 NCI collection year. The questions in the last table were created by NYS, so no national comparison data exist. All state-to-state comparisons use adjusted HSRI data, except where otherwise noted.

Legend for Comparison column:	○	⦿	●	○	●
	5 points or more below national average	**Up to 5 points below national average**	**No statistical difference from national average**	**Up to 5 points above national average**	**5 or more points above national average**
	○	⦿	●	○	●

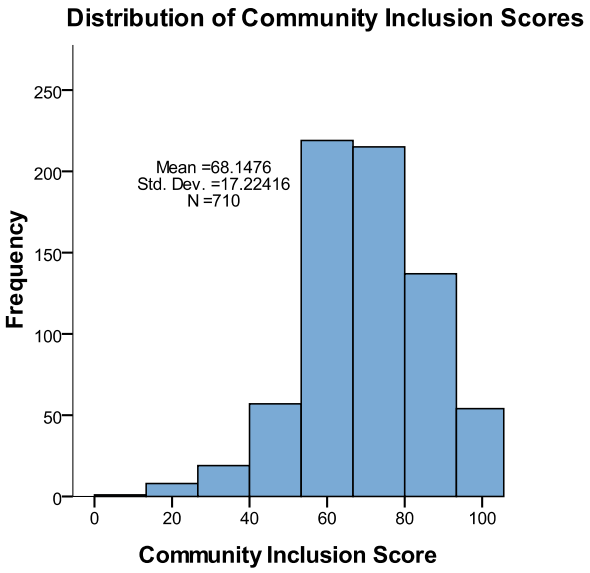
	NYS	Nat'l	Comparison
Did you go shopping recently?	92.0	93.2	⦿
Did you go out on errands and appointments recently?	96.3	96.4	●
Did you go out for entertainment recently?	87.7	88.0	●
Did you go to out to a restaurant or coffee shop recently?	89.4	90.9	●
Did you go out to a religious service or spiritual practice recently?	60.2	60.7	●
Did you go to a community meeting recently?	21.7	21.9	●
Did you go out for exercise recently?	34.7	37.4	⦿

Note: The following are NYS questions; no national data exist.	**Many or Some**
Belong to community groups?	38.9
Made friends through these community groups?	87.1 of those who belong

Note: The following is a NYS question; no national data exist.	**Yes/Sometimes**
People say they miss you when you are absent from community activity	87.4 of those who belong

Note: The following is a NYS question; no national data exist.	**Always/Usually**
People talk to you when you are at community places	63.8

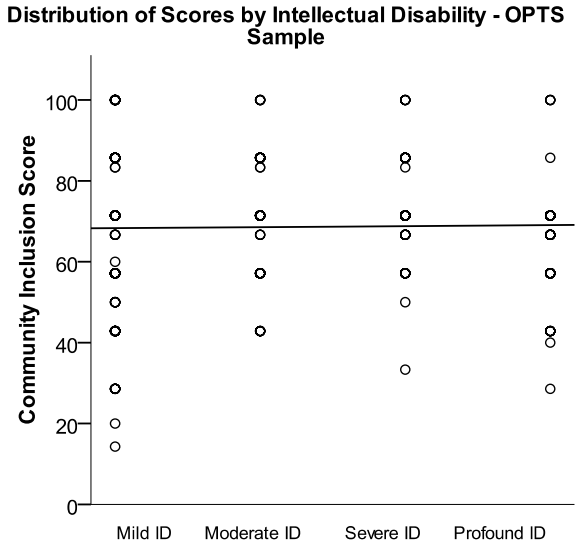
Descriptive Analysis of Community Inclusion

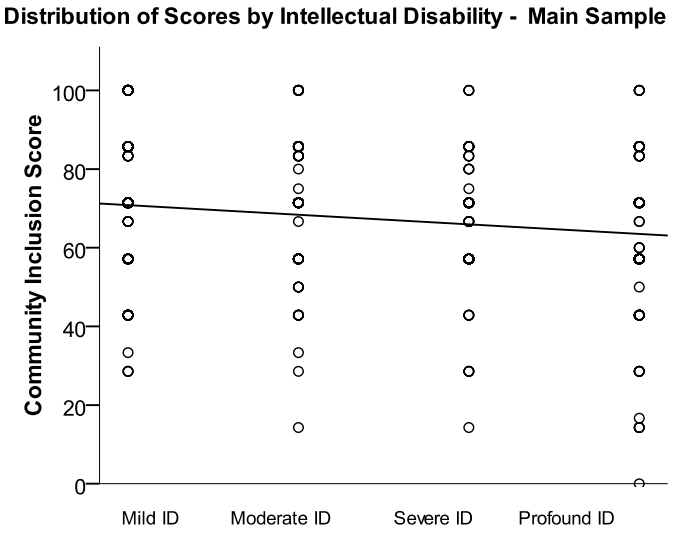


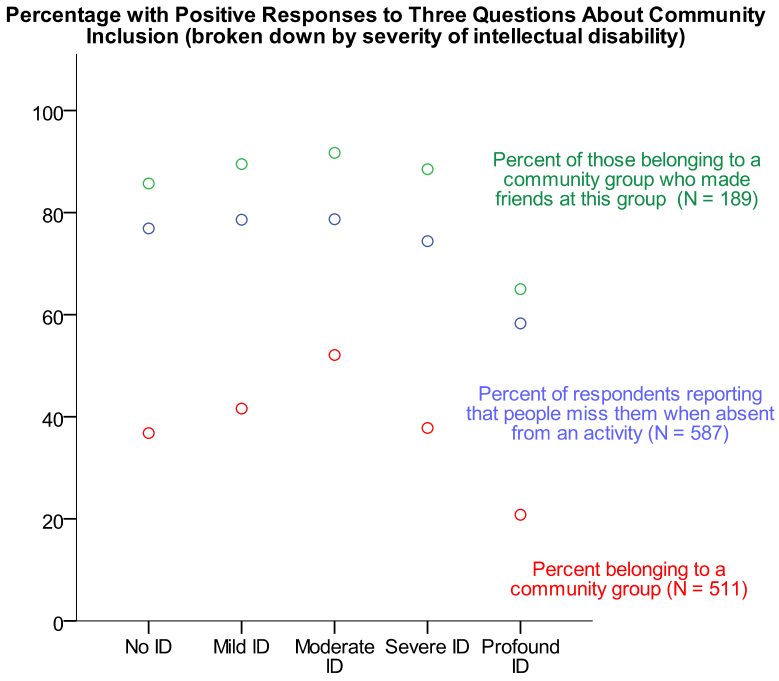
In the Consumer Survey, community inclusion can be evaluated using individual indicators as shown on the previous page, as well as through a scale which combines all seven questions to create one score. This score tells us something about the extent to which a person participates in the community. The community inclusion score falls between 0 and 100. A score of 100 means that, of the seven questions to which the person responded, the person stated that they engage in community activities regularly. A score around 50 means that, of the seven questions answered, people said that about half of the activities are done on a regular basis while the other half are not. The average score, as calculated by NYS, is 68.15. The median score is 71.43, suggesting that the data is skewed, with more people achieving high scores than low scores, as shown in the graph above. Note that this methodology might differ slightly from HSRI's.

Effects of Level of Intellectual Disability on Community Inclusion

Level of ID was not significant in predicting community inclusion scores for the OPTS sample, but did achieve significance for the main sample. This may suggest that OPTS overcame some barriers to community inclusion. As can be seen from the graphs below, there is no clear linear relationship between the score and level of ID for the OPTS sample- the best fit line is flat. For the main sample, as the ID level increases by one, the CI score decreased by about two points, as can be seen from the graph on the right (below). The fact that many OPTS projects included community participation as a desired outcome may have increased community activities for those with more severe intellectual disabilities.







The NYS questions on relationships are reported to the left, broken out by severity of ID. The pattern is the same for all three questions, with the percent of positive responses peaking for people with moderate ID. Individuals with profound ID tend to have many more negative responses compared to other individuals surveyed.

Synopsis of Relationship and Community Inclusion Analysis

NYS performs within the average range or better for all items in the relationship sub-domain. However, there is room for improvement for NYS (along with other states) to increase the percentage of people who say that they have friends they like to talk to or do things with. Arguably, this percentage should be very close to 100. Close to 40% of the individuals surveyed report feeling lonely and fewer than 75% of respondents report that friends get in touch with them and ask to do things with them. These results suggest that a sizeable portion of people we serve have small social networks and may not have relationships that are reciprocal.

New York's score on the community inclusion scale, (.692) was considered to be within the average range by HSRI. Clearly, there is room for improvement for NYS as well as many other states in this area. NYS performed worse than most states on the item pertaining to physical activity taking place in the community, with only 34.7% of people reporting that they exercise or play integrated sports. NYS had an average performance for all other items included in this scale except for the items that address shopping and exercise. Although the shopping item had a statistically significant lower score, NYS still had good achievement for this item. Other items in the community inclusion scale score close to 90% or higher with the exceptions of going to religious services, exercising in an integrated setting and going to a community meeting. Lower scores on these items might reflect individual choice not to participate in these activities or could result from the increased staff intensity required for participation.

Further analysis revealed that mobility may have an impact on participation in community inclusion activities. Individuals who are not able to self-ambulate scored roughly 11 points fewer than individuals who are more mobile (controlling for level of intellectual disability and whether the person lives with their family). One reasonable hypothesis is that participation in community sports, an item included in this scale, could drive differences in scale scores. However, other survey items besides participation in community sports also show that people who are ambulatory are comparatively more likely to engage in other types of community activities.

Type of day service was also found to have some explanatory power for some of the community inclusion items. Specifically, individuals in SEMP were more likely to report that they belong to community groups and report that people miss them when they are absent from a community activity.

Recommendations

- OMRDD will consider initiatives to help promote meaningful relationships for individuals with developmental disabilities.

The data indicate that friendships are not always reciprocal nor are individuals able to experience typical social interactions, such as dating, on a regular basis. The community inclusion analysis suggests that most people (87%) who belong to community groups make some friends. Therefore, one way to foster meaningful relationships might be through membership in community organizations.

- OMRDD must promote community inclusion for groups with increased risk of isolation. Individuals who are not mobile and/or who have more severe levels of intellectual disabilities are at risk for less community participation. OMRDD should communicate this disparity with staff and providers, and continue to explore ways to provide opportunities for community participation for these groups.

Involving individuals with more severe intellectual disabilities in community activities may pose some additional challenges; however, everyone should have opportunities for community membership and contribution.

NYS OPTS achieved equity in accessing the community for people at various levels of intellectual disability suggesting that severity of ID does not have to limit community participation. The equity achieved may have been the result of requiring an evaluation component for each OPTS project. Each project developed an evaluation plan, which often included community inclusion as an outcome.

- Improve the community inclusion section of the Consumer Survey.

The 2007-2008 Consumer Survey focused on basic questions about the type of communities activities in which people engage and was a good starting point for the measurement of community inclusion. However, it is not enough to know that individuals shop or go out to eat, rather, it is more important to understand if individuals choose the places they go in the community and if they are connecting with people other than staff or other people with disabilities. The 2008/2009 Consumer Survey has been modified to collect more in-depth information about inclusion but may not fully assess community inclusion as envisioned by NYS.

Health

The health and wellness domain contains items addressing weight, smoking habits, physical activity and attendance of routine medical appointments. NYS OMRDD added six additional questions to learn more about the health of people we serve.

Indicators of HEALTH

% All numbers are percentages %

National comparison data are from the 2007-2008 NCI collection year. The questions in the last table were created by NYS, so no national comparison data exist. All state-to-state comparisons use adjusted HSRI data, except where otherwise noted.

Legend for Comparison column:	○	⦿	●	⭘	●
	5 points or more below national average	**Up to 5 points below national average**	**No statistical difference from national average**	**Up to 5 points above national average**	**5 or more points above national average**
	○	⦿	●	⭘	●

	Yes		
	NYS	**Nat'l**	**Comparison**
Received a routine physical exam in the last year?	92.0	87.0	●
Received a gynecological exam in the last year?	57.7	49.5	●
Received a dental exam in the last six months?	62.1	52.3	●
Is weight a concern for this person? *Note: lower percentages are better	32.1	33.4	●
Does this person smoke or chew tobacco? *Note: lower percentages are better	5.2	8.0	⭘
Is this person physically inactive? *Note: lower percentages are better	26.7	22.9	⦿

Note: The following is a NYS question; no national data exist.	**Yes**
Have you been trying to control/lose weight in last 12 months?	55.3
Have you smoked or chewed tobacco in the past year?	9.0
Have you quit smoking or chewing tobacco?	27.3 (of smokers**)
Do you get enough sleep?	84.2
Do you eat healthy foods on most days?	87.4
Is your overall health good?	84.8

** Further information on smokers: **13.6%** are trying to quit**, 34.1%** tried to quit, but failed and **20.8%** did not try to quit

Synopsis of Health

As measured by the NCI items, individuals with developmental disabilities in NYS have better health than others with DD in many parts of the nation. However, individuals with DD in NYS are more likely to be physically inactive compared to the national average and one third of the respondents indicated weight was a concern.

Recommendation

- These outcomes suggest a need to promote diet and exercise as a preventative measure for future chronic health concerns, such as diabetes and heart disease.

NCI Indicators of PRODUCTIVITY

Productivity is an integral aspect of OMRDD's strategic framework which strives to assist individuals with developmental disabilities to work at paying jobs and/or participate in their communities through meaningful activities. The NCI indicators for work measure satisfaction with employment/day activities and benchmark outcomes that are important to self-advocates and families.

% All numbers are percentages %

National comparison data are from the 2007-2008 NCI collection year. The questions in the last table were created by NYS, so no national comparison data exist. All state-to-state comparisons use adjusted HSRI data, except where otherwise noted.

Legend for Comparison column:	○	◉	●	○	●
	5 points or more below national average	**Up to 5 points below national average**	**No statistical difference from national average**	**Up to 5 points above national average**	**5 or more points above national average**
	○	◉	●	○	●

	Yes		
	NYS	**Nat'l**	**Comparison**
Do you like your job or day activity?	95.2	95.7	●
Is the staff at your day program/work nice and polite to you?	93.6	93.7	●
Do people help you do or learn new things?	77.0	80.5	●
Do you want more help to do or learn new things?	70.3	62.4	Unavailable

Note: The following is a NYS question; no national data exist.	**Yes**
Do you have the chance to earn good money? (N = 214, N/A and Don't know responses = 498)	70.1
Do you work as many hours as you want? (N = 288, N/A and Don't know responses = 424)	69.5
If you are old enough to retire, can you stop working or going to day program?	66.0

Note: The following is a NYS question; no national data exist.	**At Least Monthly**
How often do you volunteer in the community?	31.7

Synopsis of Productivity

Overall, people tend to like the day services they receive. NYS performed within the average range for all items where comparison data is available. There is room for improvement in the percentage of people who say they work as much as they want and earn good money. Not surprisingly, a large majority of people in SEMP/Pre-Voc reported that they have a chance to earn good money (87.2%) compared to those in other day services (54.5%). Additionally, only 66% of respondents reported that they are able to retire and stop working or going to day programs.

Recommendation

- OMRDD should continue to support the "Employment First" initiative and increase the number of individuals with developmental disabilities who obtain and maintain employment.

People in work-related day services tend to have more choice, as measured by the choice scale developed by HSRI, which is discussed in the following section of this report. There are potentially thousands of people who are currently in non-work related day programs and hundreds of people in OMRDD's service system who have an unmet SEMP need. System-wide increased choice may be obtained through movement into work-related day services, given that individuals we serve are interested in this option.

Choice

Life Decisions and Everyday Decisions Scales

HSRI constructed two scales that measure the amount of choice a person experiences. The life decisions scale is composed of five items related to amount of choice over staffing and places where people live and work. The everyday decisions scale measures extent of choice over everyday activities such as daily schedules, free time and spending money. In the table below, items belonging to the life decisions scale have a LD placed after the survey item, whereas items belonging to the everyday decisions scale have an ED. NYS combined these two scales to create one large choice scale, for which the descriptive analysis is provided on page 18.

NCI Indicators of Choice

% All numbers are percentages %

National comparison data are from the 2007-2008 NCI collection year. The questions in the last two tables were created by NYS, so no national comparison data exist. All state-to-state comparisons use adjusted HSRI data, except where otherwise noted.

Legend for Comparison column:	○	⦿	●	○	●
	5 points or more below national average	**Up to 5 points below national average**	**No statistical difference from national average**	**Up to 5 points above national average**	**5 or more points above national average**
	○	⦿	●	○	●

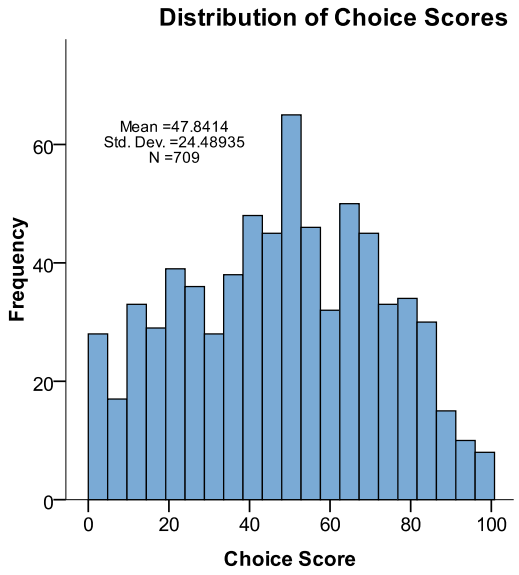
	Person Chose or Had Input		
	NYS	**Nat'l**	**Comparison**
Who chose the place where you live? LD	43.9	48.0	●
Did you choose the people you live with (or to live by yourself?) ED	38.9	41.6	●
Did you choose who helps you at home? LD	59.5	61.2	●
Who decides your daily schedule? ED	77.4	79.8	●
Who decides how you spend your free time? ED	88.5	89.9	●
Who chose the place where you work/go during the day? LD	55.1	57.9	●
Do you choose who helps you at work? LD	65.5	66.2	●
Do you choose what you buy with your spending money? ED	85.9	88.1	●
Did you choose your case manager/service coordinator? LD	55.1	56.7	⦿

	One or More		
	NYS	**Nat'l**	**Comparison**
How many places did you visit before moving where you live?	28.6	34.9	○
How many places did you visit before deciding to work/go there during the day?	31.1	36.1	⦿

Synopsis of Choice

NYS scored a 0.569 on the life decisions scale, which is within the average range of this scale relative to other states. Low scores here are disconcerting- they indicate that people are experiencing limited choice for all or some of the items on this scale. Out of all of the items in this scale, NYS did the worst (as did many states) on the number of people who chose the place where they live. Only 43.9% reported having this choice. NYS also performed below average in the proportion of people who chose their case manager/service coordinator. NYS scored within the average range on the everyday decisions scale, scoring a .774. The highest scoring state was Vermont with an everyday decisions scale score of .907. Again, this is another area where NY has the opportunity to improve.

Descriptive Analysis of Choice Scores



In the Consumer Survey, choice can be evaluated as individual indicators as shown on page 17, as well as through a scale which combines all 11 questions to create one score. This score tells us something about the extent to which a person exercises choice in his life. The choice score falls between 0 and 100. A score of 100 means that of the 11 questions to which the person responded, the person stated that he makes all decisions independently or had full choice in some way. A score of zero means that the person does not experience any choice in the area on which the survey items focus. The average score, as calculated by NYS, is 47.84. Note that this methodology might differ slightly from HSRI's.

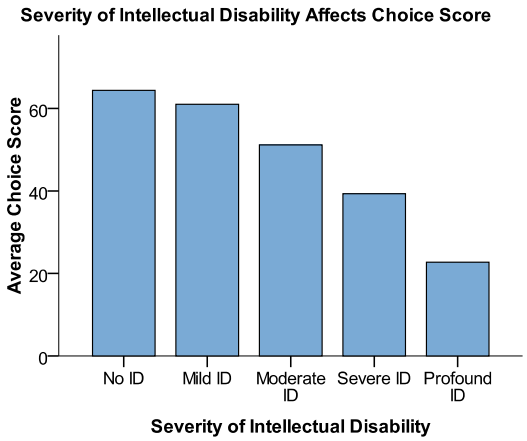
The average choice score, as calculated by NYS OMRDD, is 47.89. This score was not generated by respondents saying they had middling levels of choice for all items of the scale. Rather, for some items the most popular response was "no choice" while for other items the most popular response was "full choice". The table below shows the items for which the most popular responses were the least and most amount of choice. Items that are not listed below, have the "some choice" option as the modal response.

Full Choice	No Choice
What to buy	Home
Free time	Roommates
Daily Schedule	Home Staff
	Day Activity

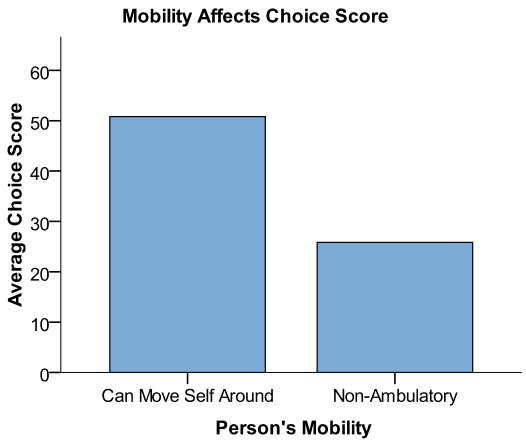
Overall, many respondents felt they have a lot of choice when it comes to everyday decisions, like what to buy and how to spend free time. If fact, for these two survey items, the majority of people (over 50% of respondents) replied that

they were able to make independent choices. Four survey items had a mode response of “no choice.” Although “no choice” was the most popular response to the survey item about choice of home staff, an almost equal number of respondents stated that though they did not choose the staff, they could request a change in staff, the “some choice” option. It is also important to note that the modal response to choice of case manager was that the case manager was assigned but a change could be requested. However, almost an equal number of people chose the “no choice” option. Since “no choice” was not the modal response to the case manager question, this item did not meet the criteria necessary to be included in the table above, but it is still an area where individuals could be provided with more choice.

Predictors of Choice Scores

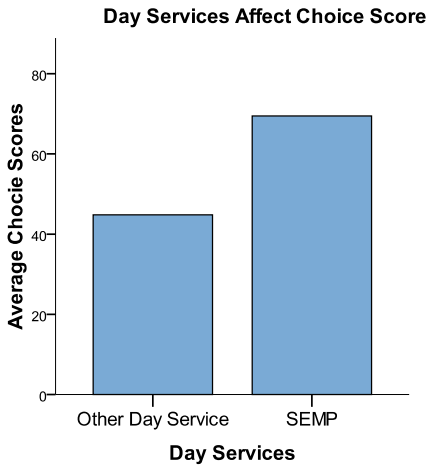


There were several factors that explained some of the variation in choice scores. Severity of intellectual disability (ID) was one variable that affected the choice score. On average, individuals with less severe ID had higher choices scores. Individuals without ID had an average choice score of 64 while individuals with a profound ID had an average choice score of 23.



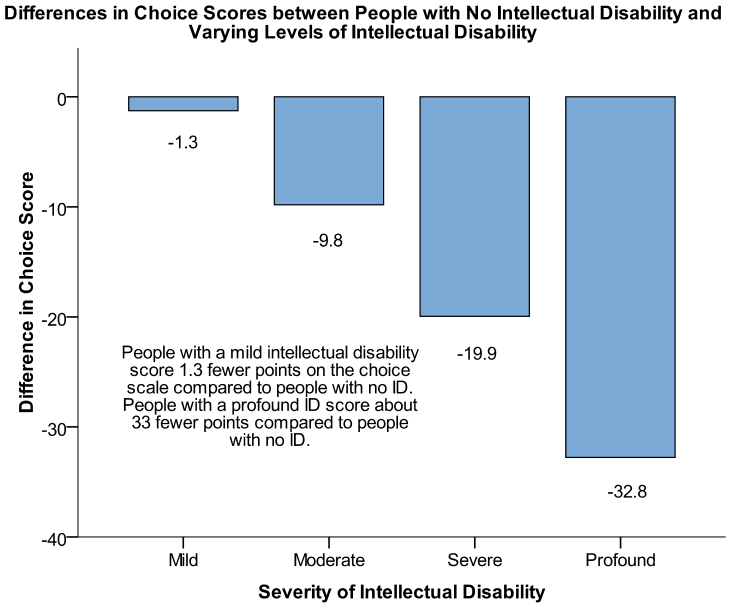
Choice scores were also affected by the person's ability to self-ambulate. Individuals who are able to move around their environment independently have an average choice score of 51 while those who are non-ambulatory had an average choice score of 26.

Individuals were divided into two groups according to living situation. Individuals who live with family or who live in an independent setting had an average choice score of 60 compared to an average choice score of 41 for individuals living in other residential settings.



An analysis was conducted for individuals receiving SEMP services. The mean choice score for SEMP recipients is approximately 69.5, while the average choice score for those in the other day categories of interest is only 45. Please note that only 55 people in the NCI sample received SEMP services, so generalizing this figure to all people receiving SEMP should be done with care.

A regression was calculated to determine the extent to which the four variables above could explain variation in the choice score. Note that the regression results differ from the descriptive analysis because regression techniques parse out the separate effects of each of the explanatory variables while the descriptive analysis is more limited. The results indicate that the three factors identified above were significant at the .05 level and can explain approximately 41% of the variation in the choice score. As the severity of ID increased by one level, the choice score decreased by roughly nine points. The level of ID was specified as: No ID, Mild ID, Moderate ID, Severe ID and Profound ID. The ability to self-ambulate increases the choice score by nine points. Living with family increases the choice score by eight points and participation in SEMP compared to other day programs increased the choice score by 12.

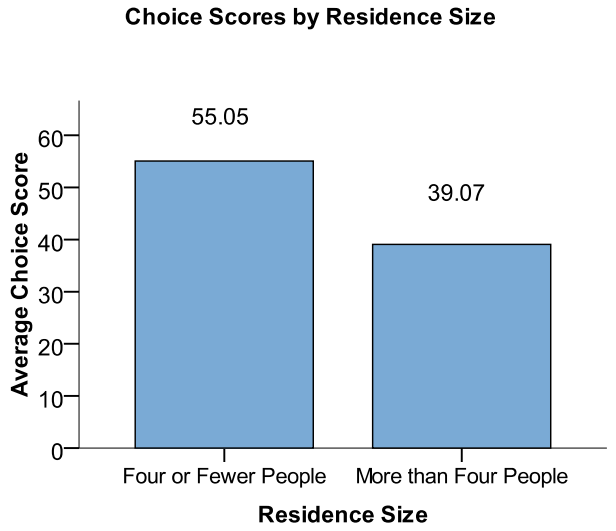


A more precise analysis of the effect of the severity of an intellectual disability illustrated varying effects in moving from one ID level to another. People with No ID are the group to which all other levels of ID are compared. The result of this analysis is represented in the graph to the left. Living arrangement (with family or not) and mobility were also included in this model and each resulted in a 10 point increase.

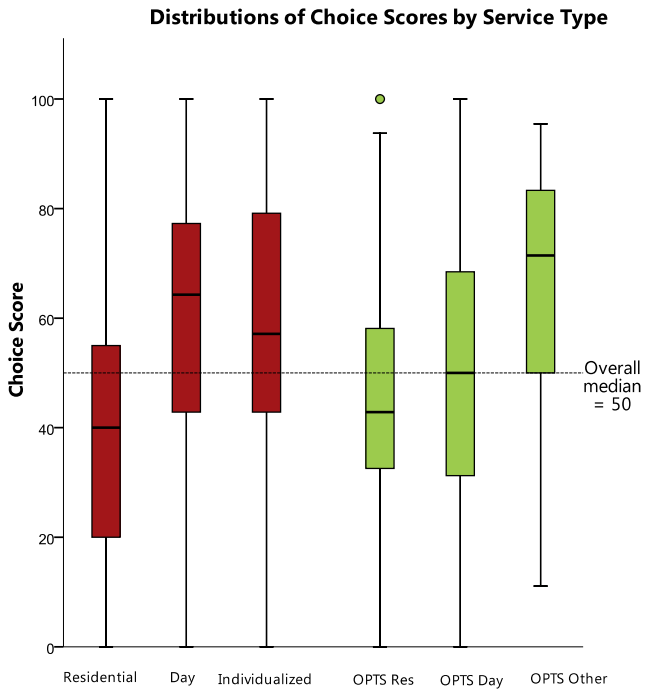
Choice Scores by Living Situation

The finding that people living with family or independently have higher choice scores than individuals living in a more congregate setting is only one part of the findings from this analysis. Further analysis was conducted to determine whether predictors of choice could be identified for people who live in *different types of congregate settings*. Individuals who live in ICFs, supervised IRAs or other supervised settings were grouped together, creating the "less independent group" whereas people living in supportive settings or receiving rent subsidies to maintain independent living were grouped together in the "more independent group".

A difference of just less than five points exists between the two groups. However, it is not this divide in living situation that drives the difference in choice score. Further analysis revealed that mobility, autism diagnosis, psychiatric diagnosis, level of functioning and size of the residence explain away the difference in choice scores between the two groups. In the model that included the variables above, a person living in a residence with four or fewer people scored seven points higher on the choice score, on average. Therefore, the size of the residence is a better predictor of the choice score than whether the residence is a supervised or supportive residence.



Choice Scores by Service Types



An analysis was done to test whether a particular OPTS service has a significantly different choice score from the corresponding non-OPTS service. For example, the choice score for those grouped in the residential category was compared to the choice score for those grouped in the OPTS residential category (OPTS Res). There is a significant difference in choice scores for day services, with the OPTS group having a lower choice score. On average, those receiving day services through OPTS had a choice score that was nine points lower than people receiving more traditional day services. There were no other significant differences in scores between OPTS service types and corresponding traditional service types.

Synopsis of Choice (cont.)

Certain characteristics of people and the type of residential and day services they receive explain variation in choice scores. Individuals with more severe intellectual disabilities and lack of mobility tend to have lower choice scores. People living with family and/or participating in SEMP tend to have higher choice scores. People living in small congregate settings have more choice compared to those living in congregate setting with more than four people.

Person Centeredness and Individualization

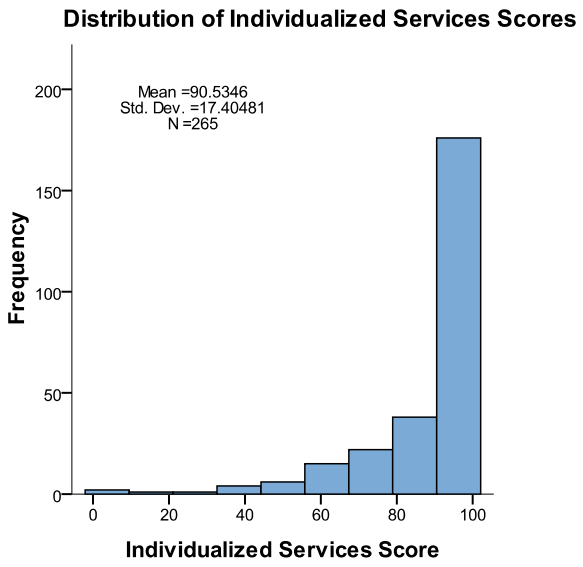
The person-centeredness scale and the individualization scale are both under development. NYS added items to the base NCI Consumer Survey in order to address these two areas. Both scales are composed of four items each. Current analysis suggests that these scales need further development, as statistical criterion (Cronbach's alpha) suggests that the questions in the scales should be refined in order to more accurately measure these two concepts. The person centeredness scale achieved an alpha of .563 while the individualized services scale had an alpha of .607. Scales achieving a 0.7 or higher are often considered sufficient to measure a concept. The goal is to eventually create scales that are accurate measures of these two concepts. Descriptive statistics are presented here, but further analysis and comment are withheld until these scales are further developed to be statistically viable.

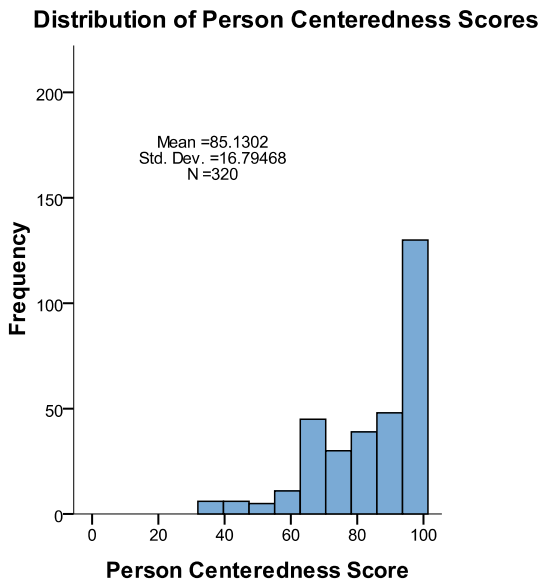
NCI Indicators of Person-Centeredness (PC) and Individualization in Planning & Supports

Note: Questions concerning PCP and Individualization of Services are NYS questions; no national data exist.	**Yes**
Individualization	
At your home, do staff work the hours that best meet your needs?	88.7
Do the staff at your home do things the way you would like?	77.2
Do the staff at your home know about your goals and needs?	91.6
Do staff at home and at day services work together to meet your goals and needs?	84.2

Person Centeredness	**Always or Usually**
When you want to make a big change in your life, do staff at home support you?	81.7
Do your planning meetings about services you get at home include the people you want there?	89.6
When you are talking about the services you get at home, do people listen & do the things you asked for?	89.2
Do the staff at your home help you to advocate for yourself?	90.9

Descriptive Analysis of PC and Individualization Scores





The scores for person-centeredness and individualization were both high, though the average score for individualization was higher than person-centeredness. Summary statistics for both scales can be found in the table below. Further analysis aimed to identify predictors of these scores will be conducted in the future, once improved scales are generated for these two concepts.

Information and Planning

Several questions were added to HSRI's National Core Indicators Consumer Survey to address whether information about services was reaching individuals in a way that is accessible and comprehensive. The table below shows the percent of people who experienced challenges accessing, processing and/or utilizing the information about services and supports. This information is especially interesting given that the data analyzed is only for individuals who were judged by the interviewer to understand the NCI questions and give consistent and valid responses, thereby creating a subset of individuals with higher cognitive capacity than the entire NCI sample. In spite of the fact that most of the individuals in the new subset (89.1%) have no, mild or moderate MR, nearly half (44.3%) did not think that the information was easy to understand (or that it was only easy to understand sometimes).

Information and Planning	**No***
Have you heard about the different kinds of services and supports that are available from your provider or OMRDD?	37.0
Is the information you have heard about available services and supports easy to understand?	44.3
Do you know enough about the services and supports available to do your own planning?	51.9

* Includes the "sometimes" response for the second question contained within the table. The other two questions had only a "yes" or "no" response option.

Further analysis revealed that individuals in a smaller setting were more likely to respond positively to these questions even accounting for differences in levels of functioning between small and large residences. The table below provides the descriptive statistics for information and planning items broken down by size of the residence.

	Percent (and number) Who Responded "Yes" by Residence Size	
	Small Residence (Four people or fewer)	*Large Residence*
Information and Planning Items		
Heard about different services…?	76.0 (N=19)	53.4 (N=39)
Information easy to understand…?	79.2 (N = 19)	40.3 (N=25)
Know enough to do own planning…?	68.0 (N=17)	36.5 (N=27)

Section 4 - Conclusion

This report reflects the results of NYS OMRDD's first year of participation in the National Core Indicators survey process. The 2007-2008 NCI initiative was designed by NYS to begin with a small sample, so that staff members were not overwhelmed with a large number of interviewees and had time to participate in training and access opportunities for technical assistance. The first year experience allowed DDSOs to become familiar with the organizational processes associated with conducting the NCI Consumer Survey. Given the success in implementing the survey, OMRDD leadership felt confident in expanding the initiative to include a much larger sample for the 2008-2009 data collection cycle. The purpose of the increased sample is to have the participation levels sufficient for comparing outcomes between subpopulations. For example, quality of life indicators can be compared by the following "break out" categories:

- DDSOs and/or other regions
- Service types
- Characteristics of the individual.

While this first report focused on framing NYS performance in terms of our People First goals and examined data from a "statewide" perspective, the 2008-2009 report will focus on examining regional differences in quality of life indicators. The next report will also contain sections written explicitly for the DDSOs, so that strengths and weaknesses among DDSOs are identified and communicated to DDSO leadership for consideration with an eye toward how to address weaknesses and share best practices. HSRI's 2008-2009 Consumer Outcomes Final Report is expected to be published by Spring of 2009. NYS OMRDD's report should be completed by Summer 2009.

On a final note, OMRDD Central Office staff members involved with NCI would like to thank all of the staff members who worked in the field, setting up and conducting interviews and doing numerous other things that made the data collection possible. The organizational learning that is occurring through NCI is not possible without the activities conducted by field staff. All of your work is valued and appreciated.