



Division of Developmental Disabilities Quality Improvement Strategy Development

Stakeholder Input Report

Developed in collaboration between
The New Jersey Department of Human Services,
Division of Developmental Disabilities
&
The Boggs Center on Developmental Disabilities,
Rutgers Robert Wood Johnson Medical School

September 2015

DDD Quality Improvement Strategy Development

Stakeholder Input

Background

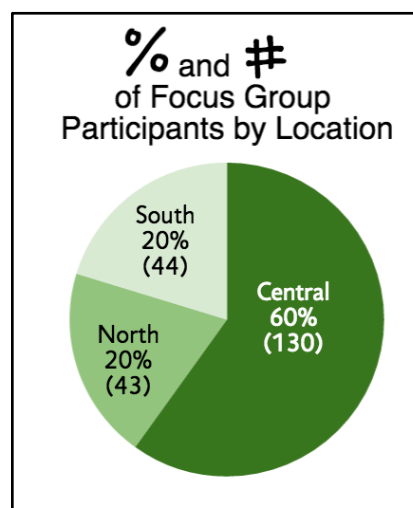
New Jersey's Division of Developmental Disabilities (DDD) is in the midst of several changes in how services and supports are funded, delivered, and evaluated. These changes include the movement to a Medicaid-only system, the shift to a fee-for-service model, and the implementation of a Supports Program. Simultaneously, New Jersey must come into compliance with the Home and Community-Based Service (HCBS) Settings Final Rule, a federal policy directive that aims to ensure full access to the benefits of community life for people with developmental disabilities receiving HCB Services.

As part of its systems change efforts, the Division has committed to developing a system-wide quality improvement strategy. This strategy will measure both compliance and the extent to which services and supports are meeting the needs and preferences of those who receive them.

Hearing from people with disabilities, their families, service providers, and other stakeholders throughout this process is paramount to learning more about what people want out of the community-based services and supports they receive, and assuring that the supports and services provided help people with developmental disabilities to achieve the lives they want. In order to obtain input from these stakeholders, the Division, through collaboration with The Boggs Center on Developmental Disabilities, Rutgers Robert Wood Johnson Medical School, conducted a series of activities that included focus groups and an electronically distributed survey.

Quality Focus Groups

Between the months of February and March 2015, the Division, in collaboration with The Boggs Center on Developmental Disabilities, conducted a series of 8 large focus groups across the state, gathering input from a total of 217 stakeholders on the topic of quality in supports and services. Sessions were held in three regions, with four sessions held in the Central region, two in the Southern region, and two in the Northern region. Participants were recruited



through an announcement sent via the DDD Communications email distribution list, which also encouraged stakeholder groups to distribute further. Participation in each of the focus groups ranged from approximately 18– 38 people per session.

The facilitated discussion was guided by a process that focused on **quality** as being defined by the person and the extent to which he or she has what is wanted and needed in life. The focus group participants included mostly family members and professionals. Seated at tables in small groups, participants responded to the following questions in three ways, including individual thought, small group discussion, and large group debrief:

1. What do people with disabilities want in their lives?
2. What do paid supporters need to do if they are to help people get what they want/need in their lives?
3. What do provider agencies need to do if they are to make sure that they offer services that help people get what they want/need?
4. Who needs to be involved in the evaluation of quality in the services provided?
 - a. What does that involvement look like?
 - b. How should DDD use their quality data they obtain?

Notes were collected from each of the small groups for use in analysis. Boggs Center staff also took notes from the discussion to capture important topics not recorded by participants at their tables. Information from these groups was compiled and synthesized into overarching themes. Each of the themes that emerged through the focus groups are listed in the charts found on the pages that follow.

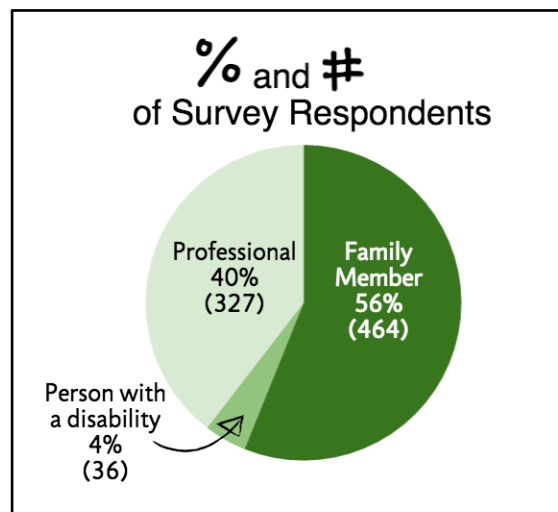
Participants identified several elements central to what people with disabilities want in their lives, and from the supports and services they receive. Some of the overarching themes expressed by participants described people with disabilities wanting the same things in life as those without disabilities, including: relationships, choice and opportunities for decision-making, independence and autonomy to the maximum degree possible, feeling respected and valued, and a sense of belonging and acceptance in the community. Focus group participants emphasized the necessity of adequate supports and services, provided by competent and trained direct support professionals, to ensure these elements are present. Health, wellness, safety, and stability were also identified as important factors in service delivery.

Several recommendations for how the Division should obtain and use data related to quality in services and supports were also provided. Among the most common suggestions for obtaining data were questionnaires and surveys completed by those receiving services and the people who know them best, meetings between those providing and those

receiving services (annual, quarterly, monthly, or as needed), internal evaluation and audits conducted within agencies, and evaluation conducted by an independent third party. Some of the specific recommendations for how data collected should be used included themes of communicating results (“publicly post outcomes”; “publish results for transparency”; “communicate back”), service and support improvement (“use data to help agency improve services”; “to determine weaknesses and make changes accordingly”), and identification of training and professional development needs (“education to improve”; “to implement change regarding more training”). A frequent suggestion from participants was the use of data to create a “Provider Report Card.”

Quality Improvement Stakeholder Survey

The themes determined through the analysis of focus group input were used to guide the development of a **Quality Improvement Stakeholder Survey**, distributed electronically to reach a wider number of respondents. This survey utilized many of the same questions asked of focus group participants, with the themes that emerged from the focus groups serving as the response selections for the survey’s multiple-choice questions. Survey respondents needed to complete the survey in its entirety for their responses to be included.



The feedback compiled from this survey, completed by 827 stakeholders, will help shape the future direction of the Division’s quality improvement initiatives.

What do people with disabilities want in their lives?

<i>What do people with disabilities want?</i>	Overall n = 827	Person w/ DD n = 36	Family Member n = 464	Professional n = 327
Dignity & Respect	48%	56%	38%	61%
Safety & Security	47%	31%	52%	41%
Consistency & Stability	44%	22%	48%	42%
Competent Support	44%	28%	51%	37%
Choice & Control	42%	28%	34%	54%
Happiness	37%	53%	38%	35%
Meaningful Activities	36%	19%	42%	28%
Housing	35%	31%	43%	25%
Relationships	30%	25%	27%	36%
Be Valued	28%	44%	23%	35%
Employment	27%	39%	30%	21%
Community Inclusion	23%	19%	21%	27%
Independence	22%	47%	18%	25%
Opportunities to Grow	17%	22%	18%	14%
Lives like people without disabilities	15%	31%	13%	16%

Survey respondents were asked to select the five items they thought best represented what people with disabilities want in their lives. Overall, the five most frequently selected responses were **Dignity & Respect** (48%), **Safety & Security** (47%), **Consistency & Stability** (44%), **Competent Support** (44%), and **Choice & Control** (42%). Significant variations existed in responses based on respondent.

Among family members (n=464), the most common responses were **Safety & Security** (52%), **Competent Support** (51%), **Consistency & Stability** (48%), **Housing** (43%), and **Meaningful Activities** (42%).

Responses by professionals (n=327) closely mirrored overall responses, with the most frequently selected responses including **Dignity & Respect** (61%), **Choice & Control**

(54%), **Consistency & Stability** (42%), **Safety & Security** (41%), and **Competent Support** (37%).

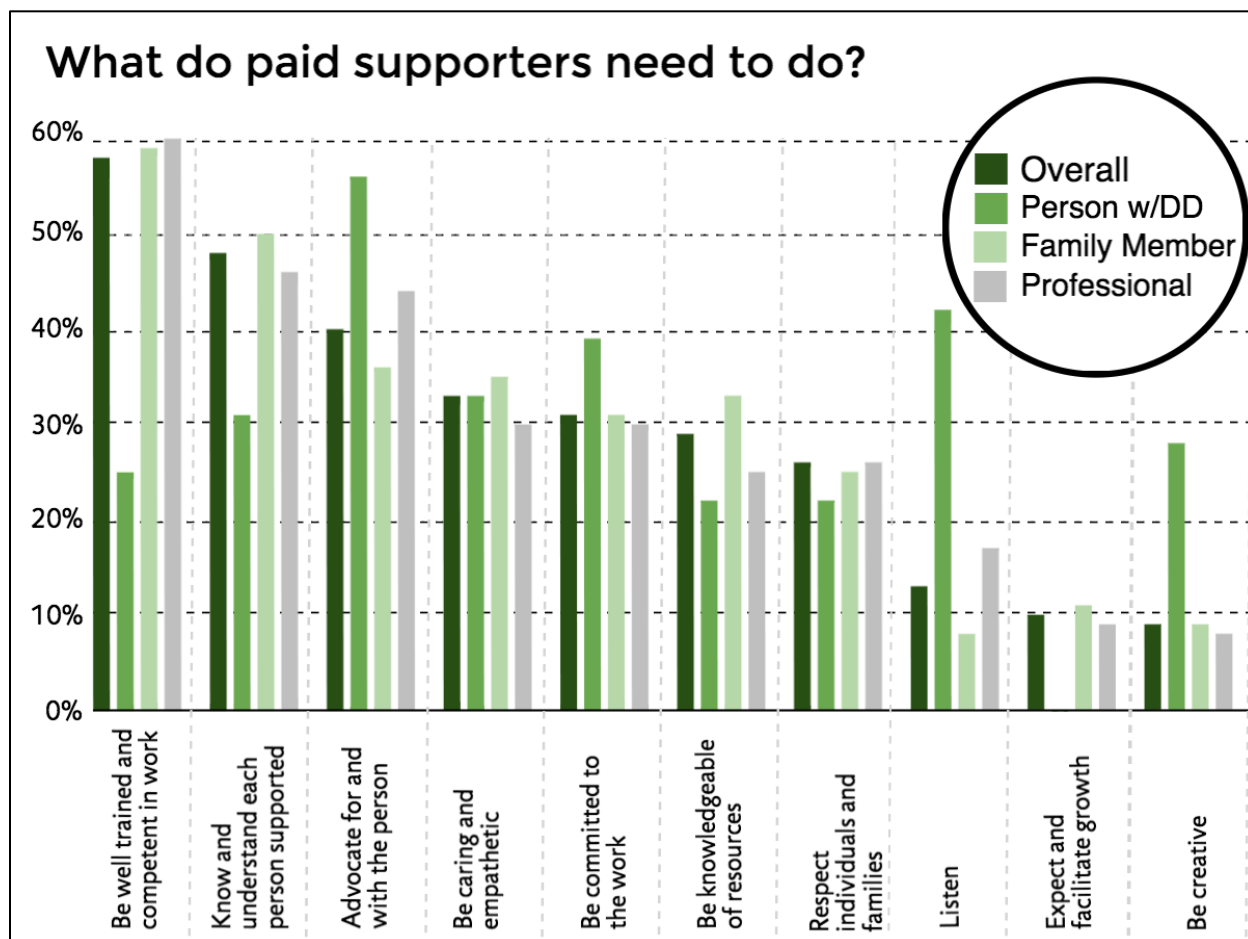
Though individuals with developmental disabilities represented a much smaller portion of respondents (n=36) than either family members or professionals, responses for this group demonstrated the greatest variation from overall responses. Individuals with disabilities reported wanting **Dignity & Respect** (56%), **Happiness** (53%), **Independence** (47%), to **Be Valued** (44%), and **Employment** (39%).

Survey respondents were given an opportunity to provide responses outside of the multiple-choice options listed. Of the 18 comments received, the most common included the need for transportation as well as medical and dental care. Some respondents commented that they would have chosen “all of the above.”

What do paid supporters need to do if they are to help people get what they want/need in their lives?

Survey respondents were asked to select the three most important things that paid supporters (Direct Support Professionals) need to do if they are to help people get what they want and need in their lives. Both family members and professionals believed that in order for people with disabilities to get what they want and need in their lives, paid supporters need to **be well trained and competent in work** (59% of family members and 60% of professionals), **know and understand each person supported** (50% of family members and 46% of professionals), and **advocate for and with the person** (36% of family members and 44% of professionals).

Individuals with developmental disabilities felt that in order to be supported to get what they want and need in their lives, paid supporters need to **advocate for and with the person** (56%), **listen** (42%), and **be committed to the work** (39%).



Survey respondents were given an opportunity to provide responses outside of the multiple-choice options listed. Of the 24 comments provided, 10 focused on the need for Direct Support Professionals to be compensated fairly and appropriately. Other comments suggested specific training areas, highlighted the need for job security and health insurance, and emphasized knowledge of and ability to support individuals' access to resources in the community. Some respondents commented that they would have chosen "all of the above."

What do provider agencies need to do to ensure that they offer services that help people get what they want/need?

Survey respondents were asked to select the three most important things provider agencies need to do to ensure that the services they offer help people get what they want and need in their lives. Overall, survey respondents felt that provider agencies need to **ensure that staff are well-trained (52%)**, **understand the needs of the people served (42%)**, and **hire qualified staff (41%)** to ensure the services they offer help people get

what they want and need. Family members' responses mirrored overall responses at 50%, 42%, and 44% respectively.

Responses from professionals echoed the need to **ensure that staff are well trained** (56%) and **understand the needs of the people served** (43%). Consistent with comments submitted for the previous question, the third most common response from professionals was for agencies to **provide staff a living wage and benefits** (37%).

Individuals with developmental disabilities responding to the survey felt that, in order to ensure services help people to get what they want and need, provider agencies need to **hire qualified staff** (47%), **ensure that staff are well-trained** (39%), and **request and listen to input from people using services and their families** (39%).

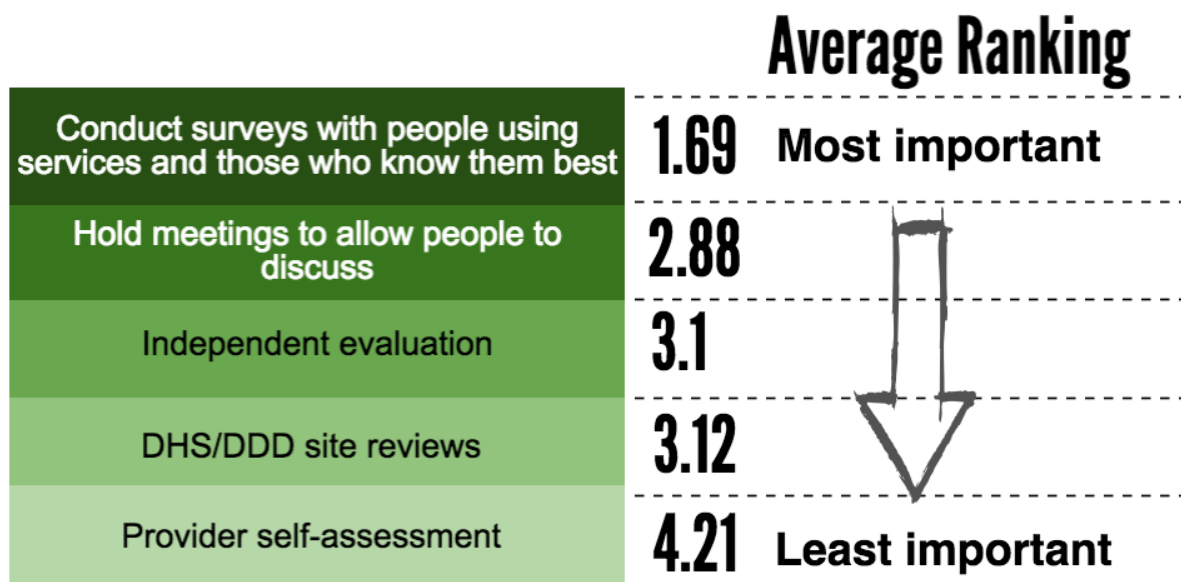
<i>What do provider agencies need to do?</i>	Overall n = 827	Person w/ DD n = 36	Family Member n = 464	Professional n = 327
Ensure that staff are well-trained	52%	39%	50%	56%
Understand the needs of the people served	42%	36%	42%	43%
Hire qualified staff	41%	47%	44%	35%
Provide staff a living wage and benefits	34%	22%	33%	37%
Request and listen to input from people using services and families	28%	39%	30%	25%
Regularly communicate with the people served and their families	27%	19%	29%	25%
Individualize services	24%	11%	22%	27%
Provide many options and choices in services	23%	36%	24%	20%
Advocate	19%	31%	17%	20%
Seek out additional funding	7%	11%	6%	7%

Survey respondents were given an opportunity to provide responses outside of the multiple-choice options listed. Of the 24 comments provided, the most common identified the need for communication at many levels, both within the organizational structure and between agency representatives and those receiving supports and services. This included

interacting with, requesting input from, and listening to individuals receiving services (including those who don't use speech) and their families. Some respondents commented that they would have chosen "all of the above."

How should the quality of supports and services be evaluated in DDD's Quality Improvement Strategy?

Survey respondents were asked to rank the evaluation methods listed in order from 1 (most useful) to 5 (least useful). Overall, respondents felt that **conducting surveys with people using supports and services and those who know them best** was the most useful method of evaluating quality, followed by **holding meetings to allow people to discuss, independent evaluation, and DHS/DDD site reviews**. **Provider self-assessment** was viewed as the least useful method for evaluating the quality of supports and services. There was little variation based on respondent.



Who should be involved in evaluating the quality of supports and services?

Survey respondents were asked to rank the importance of those who should be involved in evaluating the quality of supports and services in order from 1 (most important) to 7 (least important). Overall, respondents selected **people using services** as the most important to have involved in the evaluation of quality of supports and services, followed by **family members, guardians, DSPs/Agency staff, DDD/State staff, and Support Coordinators**.

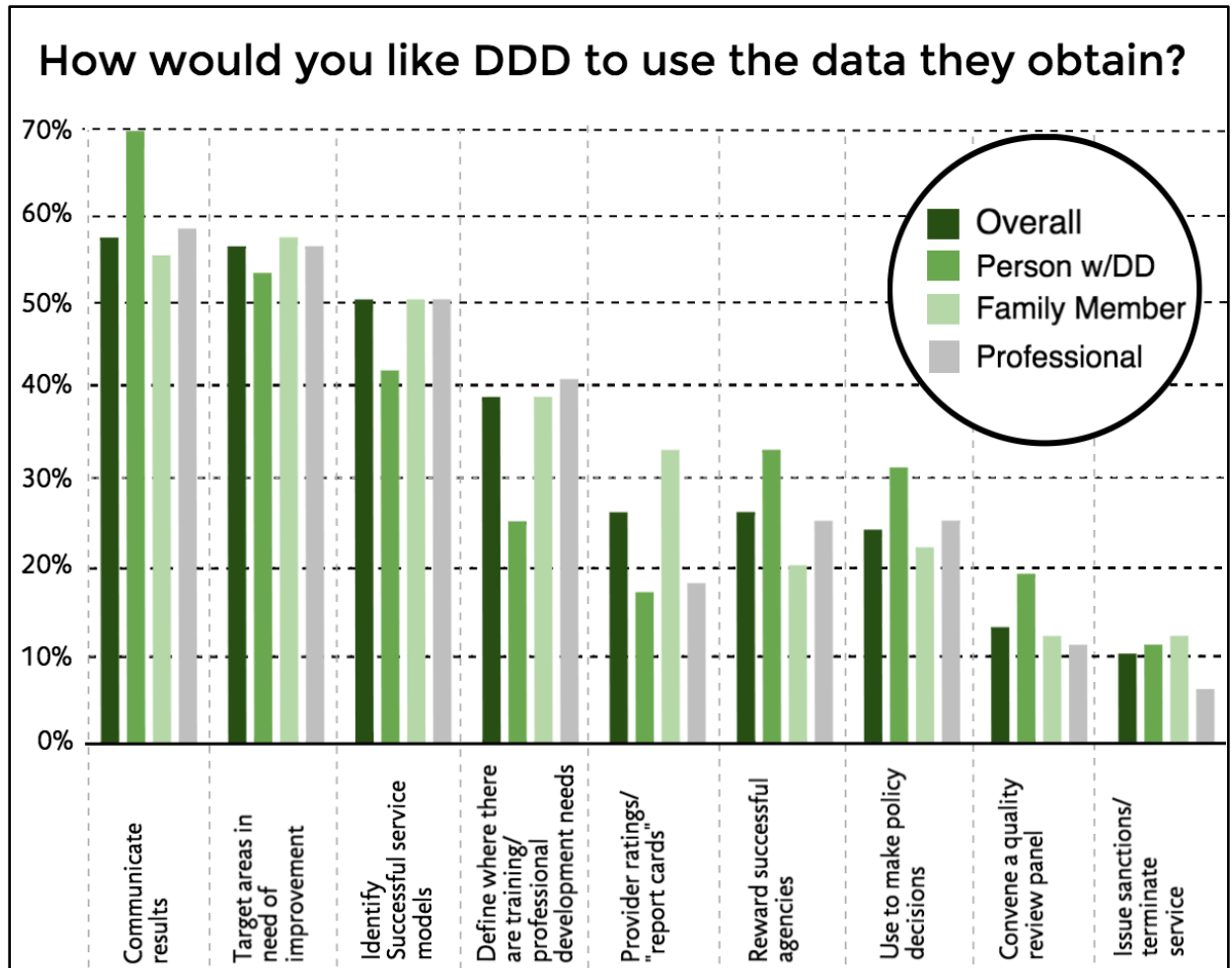
It was least important among respondents to have **provider agency leadership** involved in evaluating the quality of supports and services.

	Overall	Person w/DD	Family Member	Professional	Average Ranking
People using services	2.64	3.58	2.99	2.04	
Family members	2.68	2.64	2.33	3.19	
Guardians	3.29	3.31	2.91	3.83	
DSPs/Agency Staff	4.05	4.06	4.12	3.94	
DDD/State Staff	4.6	3.42	4.74	4.54	
Support Coordinators	5.14	5.5	4.93	5.42	
Provider Leadership	5.58	5.5	5.97	5.04	

Survey respondents were given an opportunity to provide suggestions for others that should be involved in the evaluations of quality. Of the 112 responses provided, the most frequent suggestion was to have an **independent evaluator** involved in the evaluation of quality. This included accrediting bodies, evaluation and oversight committees, independent researchers, Ombudsman, independent evaluation contractors, and legal advocates. Several of the suggestions recommended the involvement of **specialists, clinicians, and professionals** including doctors, mental health providers, behaviorists, speech therapists, occupational therapists, and physical therapists. The involvement of **advocacy organizations** and **self-advocacy groups** was also cited frequently. A smaller number of responses suggested the involvement of community members, including neighbors, in the evaluation of quality in supports and services.

How would you like DDD to use the data they obtain?

Survey respondents were asked to select the three most important uses of the quality data obtained by the Division. Overall, respondents would most like the Division to **communicate results** (57%). Nearly as important to survey respondents as communicating the results of the data obtained, survey respondents felt that the data obtained should be used to **target areas in need of improvement** (56%) and to **identify successful service models** (50%).



Survey respondents were given an opportunity to provide recommendations for other ways the Division should use the quality data obtained. Of the 102 responses submitted, the most common underscored the need to **communicate results** to stakeholders. Several respondents suggested that data be used not only to identify successful service models, but also to **create benchmarks** based on successful practices and **replicate successful models**. Other commonly cited recommendations included **identifying training needs**, **developing a framework to improve service delivery**, **implementing change**, and **identifying unmet needs**. Some respondents commented that they would have chosen “all of the above.”

Summary:

The stakeholder focus groups, survey, and this subsequent report are starting points for the development of a comprehensive quality strategy. A noted limitation of these initial efforts is the low response of people with developmental disabilities, and efforts will be taken to expand this critical voice moving forward. The Division plans to use the information provided in this report, along with New Jersey policies and regulations, and the requirements and rules set forth by the Centers for Medicare and Medicaid services to develop a quality strategy that reaches across both the Community Care Waiver and the Supports Program.

Next Steps:

The Division plans to take the following immediate next steps. Data from the most recent National Core Indicators (NCI) report will be reviewed and constituents will be provided with a report that provides a snapshot of the extent to which people with disabilities are achieving what those participating in the focus groups and survey described as important to their lives. The NCI is a tool used by state developmental disability agencies, like DDD, to measure and track performance. It is important to note that currently the New Jersey NCI data reflects, for the most part, the experiences of those receiving support through the Community Care Waiver (CCW) and does not capture information about the lives of people receiving services through other funding sources. Given this, the Division plans to expand use of the NCI survey to those that will receive services through the Supports Program.

The Division will review the information presented in this report, the Centers for Medicare and Medicaid Services (CMS) Quality Framework, the HCBS rule, and nationally recognized quality measures to determine potential performance indicators and methods of measurement moving forward. The Division will continue to seek input from stakeholders, including people with developmental disabilities, families, and provider agencies, throughout development of the quality strategy. As part of the long-term strategy, a quality council will be established to review data, set priorities, and provide input into needed changes in policy and practice on an ongoing basis.