

**Supportive Housing Association
of New Jersey (SHANJ)
NJ Council on Developmental Disabilities
Grant 2018**

**Building the Foundation for Housing,
Services, and Supports:
Best Practices Opportunities
for People with Intellectual and
Developmental Disabilities**

Best Practices Executive Summary

Individuals with developmental disabilities and their families, along with housing developers, service providers, legislators, regulators and other government partners, have redefined community living for people with special needs. There is an increased demand for individually designed supports integrated into the mainstream of every community.

SHA conducted nationwide research to survey which best practices will effectively enhance the resources and navigation of the current supportive housing system. Research involved examining policies, funding, service delivery, training, and resources within New Jersey and across the country. The term “best practice” refers to a procedure that has been shown by research and/or experience to produce optimal results and that is established or proposed as a standard suitable for widespread adoption. To accomplish these objectives, SHA has drawn upon the expertise of our grant partners including The Arc of NJ, Autism NJ, The Housing and Community Development Network of NJ, and Autism Speaks, as well as local and national leaders. Deborah Wehrle, the author of SHA's housing publications, was responsible for the research and writing of this report. The report contains a description of applicable best practices, examples of implementation, background resource material, and specific recommendations for implementation in New Jersey.

SHA appreciates the funding provided by the NJ Council on Developmental Disabilities (NJCDD) to conduct this research and develop this report. The contents of this report, however, do not necessarily reflect the opinions of the NJCDD.

Recommendation Summary

1. Person-Centered Thinking, Planning, Practice and Implementation are Incorporated into All Aspects of Service Delivery.

Recommendations:

- ✓ Regulators and service providers review their practices and provide all personnel with increased training regarding Person-Centered Practices and implementation.
- ✓ Increase the proficiency for individuals and their families in Person-Centered Planning through training and webinar opportunities that promote networking and self-advocacy.
- ✓ Require that all personnel, especially Support Coordinators and intake workers, integrate Person-Centered Planning concepts into all aspects of their work.
- ✓ Provide increase training on the needs of people with significant challenges (i.e. behavioral, profound cognitive and/or medical) so all professionals can meet their needs and support them through a robust Person-Centered Planning process.

2. Self-Direction and Budget Authority Promotes Consumer Choice

Recommendations:

- ✓ Continue to promote self-direction, self-advocacy and self-determination for individuals with I/DD.
- ✓ Review funding system and regulations for needed updates.
- ✓ Review the tier budgets for individuals and rate setting for vendors and establish a mechanism for ongoing updates to assure that sufficient funds are available to support individuals with I/DD.
- ✓ Provide line item flexibility within individual budgets so that funds can be fully utilized for approved services.

3. Microboards™ Support Individuals with Planning, Advocacy, and Plan Implementation over a Person's Lifespan.

Recommendations:

- ✓ Develop options for support when families can no longer assist individuals with planning, decision-making, and self-direction.
- ✓ Explore options to utilize Microboards™ to support individuals in planning and decision-making.
- ✓ Provide technical assistance to individuals and families regarding Microboards™.

4. Support Coordination and Support Brokerage Assist Individuals with Person-Centered Planning to Attain Life Goals.

Recommendations:

- ✓ Empower individuals through choice, self-direction, and individual budgets, resulting in person-centeredness and provider accountability.
- ✓ Manage Support Coordinator workloads to have small caseloads and limited administrative responsibilities so that focus is primarily upon individual and not system needs; delegate data collection and quality assurance monitoring responsibilities to other entities.
- ✓ Address the low supply of Support Brokers by establishing a viable reimbursement rate for these providers, so that families may access this specialized service.
- ✓ Educate individuals and their families about the service option of support brokerage.
- ✓ Utilize Support Brokers with specific knowledge to research and secure necessary services when the family or the individual with I/DD is not able to do so independently.

5. Coordinated Healthcare and Wellness Education Is Easily Accessible

Recommendations:

- ✓ Implement the "Healthy Homes and Medical Homes" concepts that offer a combination of primary healthcare and wellness services incorporated into residential settings or neighborhoods for individuals with developmental disabilities.

6. Options Incorporating Best Practices Are Available to Meet the Intensive Support Needs of Those with High Acuity

Recommendations:

- ✓ Develop innovative models to safely treat the intensive medical and/or behavioral health needs of individuals with I/DD.
- ✓ Develop an urgent response system with a team of experts who are empowered to make decisions and access available supports when a person with complex needs has an emergency need for residential services.

7. The System is Invested in a Strong Direct Support Workforce.

Recommendations:

- ✓ Continue to advocate for increased wages for direct support personnel.
- ✓ Establish a career path for the DSP workforce.
- ✓ Promote incentives for DSPs including education, training, and increased credentials.
- ✓ Establish mechanisms for recruitment of personnel to work as direct support employees.

8. Technology, Including Smart Home Technology, Universal Design Advance Independence, and Reducing Reliance upon Personal Assistance

Recommendations:

- ✓ Publish a database of experts in technology who can consult and plan individually for persons with I/DD to achieve personal objectives for independence.
- ✓ Establish reasonable guidelines that protect safety and privacy when using technology in licensed and unlicensed facilities.
- ✓ Incorporate revised universal design features into building standards, providing reasonable accommodations for accessibility, aging in place, and smart home technology.

- ✓ Require housing developers to incorporate revised universal housing design features into all new government funded projects.
- ✓ Develop incentives to build aging in place and smart home technology adaptations into a percentage of all new construction sites.
- ✓ Promote funding for modifications to existing housing stock to facilitate the needs of people as they age or become physically disabled.

9. Community Integration is Fostered When Designing Housing and Supports.

Recommendations:

- ✓ Encourage development of new housing and supportive service models that incorporate community integration into the design.
- ✓ Educate individuals, families, and professionals, especially Support Coordinators, regarding additional housing models, including co-housing, co-ops, and shared-living that promote community integration.
- ✓ Supply technical assistance for those developing supported housing models that promote integrated community.
- ✓ Test and determine the efficacy of the NJ State Transition Plan's survey tool in evaluating the quality of community integration across the full continuum of residential options.
- ✓ Expand capacity by encouraging family purchasing of housing for integrated housing models such as shared living and co-ops.

10. Build the Capacity of Affordable Housing through Funding Housing Development and Rental Assistance

Recommendations:

- ✓ Replenish the NJ Special Needs Housing Trust Fund or other dedicated funding to provide funding for affordable housing development.
- ✓ Seek funding for the development of additional affordable housing, rental assistance, and supportive services
- ✓ Fund a combination of support available simultaneously for affordable housing development, along with rental assistance vouchers and supportive housing services, to address the population with special needs.
- ✓ Promote family-donated housing to provide additional, permanent, sustainable housing.

11. Simplify Ease of Access and Referral to Service Delivery

Recommendation:

- ✓ Implement a No Wrong Door approach to intake and eligibility across funding systems.

- ✓ Cross train professionals about other services beyond their particular area of expertise to accommodate a No Wrong Door approach.
- ✓ Simplify the application process to a common application to apply for supportive services, housing, and rental assistance vouchers simultaneously.
- ✓ Advocate for additional HUD funded rental assistance and continue to provide DHS/DDD rental assistance until individuals can secure them.
- ✓ Utilize Small Area Fair Market Rates when determining DHS rental subsidies for specific locations.
- ✓ Develop an effective referral system to match people to available affordable housing options.
- ✓ Design a coordinated referral system to match up the availability of vacancies within DDD waiver services for those on the waiting list.

12. Research and Data Analysis Drive Planning and Policy Decision-Making

Recommendation:

- ✓ Designate funding for data scientists to identify, collect and analyze data to report outcomes and benchmarks by which future progress can be measured.
- ✓ Use research and objective data to drive decision-making and policy development.
- ✓ Allocate resources to expand funding, models, settings and housing development based upon assessment of needs and preferences.

INTRODUCTION

Individuals with developmental disabilities and their families, along with housing developers, service providers, legislators, regulators and other government partners, have redefined community living for people with special needs. There is an increased demand for individually designed supports integrated into the mainstream of every community. Housing must be affordable, accessible, and safe. With recent systemic changes in New Jersey, more choice and more responsibility have been placed upon individuals to secure these resources.

The Journey to Community Housing with Supports, published by SHA in 2016, examined models from traditional to innovative, providing needed guidance to individuals and families. This guide describes self-direction as well as agency-provided services. Research for the guide revealed that there are finite resources and complex systems to navigate. Building upon its existing housing guide, SHA has utilized the grant from the NJ Council on Developmental Disabilities to provide in depth resources to access housing and supports through training, informational bulletins, video, and this best practice report.

To complete this report, SHA conducted nationwide research to survey which best practices will effectively form the basis of determining a strategy for advocacy and set policy priorities. To accomplish these objectives, SHA has drawn upon the expertise of our grant partners including The Arc of NJ, Autism NJ, The Housing and Community Development Network of NJ, and Autism Speaks, as well as local and national leaders. Research involved examining policies, funding, service delivery, training, and resources within New Jersey and across the country. We sought input from individuals and their families, professionals, governmental leaders, and policy developers. Deborah Wehrlen, the author of SHA's housing publications, was responsible for the research and writing of this report.

This Report contains a description of applicable best practices, examples of implementation, background resource material, and specific recommendations for implementation in New Jersey. Within this document, the term “best practice” refers to a procedure that has been shown by research and/or experience to produce optimal results and that is established or proposed as a standard suitable for widespread adoption. SHA and the grant partners will advocate for the design, funding, and implementation of these practices to enhance the supportive housing system.

SHA appreciates the funding provided by the NJ Council on Developmental Disabilities (NJCDD) to conduct this research and develop this report.

Best Practices

1. Person-Centered Thinking, Planning, Practice and Implementation are Incorporated into All Aspects of Service Delivery.

Person-Centered Thinking, Planning, Practice, & Implementation (PCP): Person-Centered thinking or planning is a process that works *with* the individual. It focuses on their interests, what they do well, and what is important to them now and in the future. PCP engages the person in the decision-making process so that the person's dreams, goals, and priorities remain central to any plan that will affect them ("Glossary of Terms").

Person-Centered Planning and Implementation involves the development of an individual's goals and the respective personal outcomes, resulting in a rich life for the individual. People with intellectual and developmental disabilities (I/DD) want to have meaningful friendships, make decisions about their own lives, and hold valued social roles in the community in which they live. To accomplish the best practice of Person-Centered Planning and Implementation, outcomes are driven by personal preferences and dreams rather than based upon what programs and services are available. Individuals with I/DD and their families are at the foundation of this process. Professionals and the publicly funded systems should support individuals with services that lead to achieving their life goals (Roberts).

While the concepts of person-centeredness have been an inspirational philosophy for disability services for decades, implementation of these principles still needs cultivation at all levels, particularly with government policy makers, service providers, and the greater empowerment of individuals and families. All professionals need to respect and promote these principles and may need further education to do so.

No Wrong Door Initiative

The **No Wrong Door** approach provides individuals with a universal gateway to community services and government programs. It enables clients to approach the agency with the problem they need to address, rather than a preconceived idea of the programs or services they think that they should receive ("No Wrong Door").

Funded through the federal Administration for Community Living and four other states, the "No Wrong Door Projects of National Significance" demonstrated how person-centered thinking, planning, and practices can form the basis for best practices for all populations being assisted by their services. Rather than using techniques that tended to screen out or re-direct people to other agencies, this consumer-directed approach trains all staff on the full array of services individuals may need. Professionals are knowledgeable about all aspects of service delivery and how to streamline access to services. The first agency that interacts with the consumer assesses the need, explains what resources exist, and advises the person on how to access the services. For example, if a person with I/DD needing supportive housing contacts the vocational rehabilitation agency, those intake workers are equipped to supply them with information about the state agencies that can assist them with housing eligibility, funding, and residential services. Whatever door is the first place of entry into the service system, staff will

advise the consumer of all the options that might be available to them in the state's service delivery system (“Aging and Disability Resource Centers Program/No Wrong Door System”).

When employing the techniques of person-centered thinking and practice, all personnel are trained to encourage self-advocacy and self-direction. They listen to each consumer in whatever way they can express their needs and preferences. Systems are designed with flexibility to address service requests rather than offering a singular or siloed approach to service delivery. All professionals encourage individuals to plan and use these resources to address their own needs and preferences (*Key Elements of a NWD System of Access to LTSS for All Populations and Payers*).

Recommendations:

- ✓ Regulators and service providers review their practices and provide all personnel with increased training regarding Person-Centered Practices and implementation.
- ✓ Increase the proficiency for individuals and their families in Person-Centered Planning through training and webinar opportunities that promote networking and self-advocacy.
- ✓ Require that all personnel, especially Support Coordinators and intake workers, integrate Person-Centered Planning concepts into all aspects of their work.
- ✓ Provide increased training on the needs of people with significant challenges (i.e. behavioral, profound cognitive and/or medical) so all professionals can meet their needs and support them through a robust Person-Centered Planning process.

References:

“Aging and Disability Resource Centers Program/No Wrong Door System.” *ACL Administration for Community Living*, 30 Aug. 2017, <https://acl.gov/programs/connecting-people-services/aging-and-disability-resource-centers-programno-wrong-door>.

Key Elements of a NWD System of Access to LTSS for All Populations and Payers. Administration for Community Living, <https://nwd.acl.gov/pdf/NWD-National-Elements.pdf>. Accessed 8 Dec. 2018.

Roberts, Russell. “Community of Practice: Focusing on Life Span Supports for Self-Advocates and Their Families.” *Umkc.Ihd*, 2017, <https://ihd.umkc.edu/community-of-practice-focusing-on-life-span-supports-for-self-advocates-and-their-families/>.

Amado, Angela N., and Marijo McBride. "Increasing Person Centered Thinking: Improving the Quality of Person-Centered Planning." *University of Minnesota, Institute on Community Integration*, 2001, <https://rtc.umn.edu/docs/pcpmanual1.pdf>.

"Person-Centered Planning." *Pacer's National Parent Center on Transition and Employment*, <https://www.pacer.org/transition/learning-center/independent-community-living/person-centered.asp>. Accessed 4 Jan. 2019.

2. Self-Direction and Budget Authority Promotes Consumer Choice

Self-directed services: Self-direction refers to an approach of delivering home and community-based services (HCBS) that allows individuals to directly control a range of those services and supports—with the assistance of representatives of their choice—based on their own preferences and needs. The central goal of self-direction is to maximize an individual's opportunities to live independently in the most integrated, community-based, setting of his or her choice.

Individual Budgets: An individual budget expresses, in dollar terms, the amount of funding deemed necessary to meet the anticipated service and support needs of an individual with a disability who is enrolled in HCBS. When services are self-directed, the individual decides how all, or a defined portion, of his or her individual budget is to be used (Gettings et al.).

A natural outcome of person-centered planning is self-direction with individual choice and control. Individuals with I/DD can learn self-advocacy skills such as decision-making and assertiveness through trainings provided by the NJ Council on Developmental Disabilities, The Arc, and The Elizabeth M. Boggs Center. Families may initially lead the process and then increasingly empower and defer to the person with the disability as he or she learns to self-advocate and assume the responsibilities of self-directing to the fullest extent possible.

Self-direction and self-advocacy have and will continue to change the face of service delivery. Individuals, families, guardians, and support coordinators have become more informed consumers. Specifically, they can request and should expect objective measures of a provider's performance. They can then use this information and their preferences to select service providers. With more consumer choice, service providers are likely to increase their attention to consumer satisfaction and the quality of their services (Walker et al.).

The National Leadership Consortium on Developmental Disabilities of the University of Delaware and Optum are studying self-direction through "The Spark! Initiative" (Bailey and Gilden). Working in collaboration with national leaders, they are surveying individuals and service providers to eliminate deterrents and promote self-determination ("A Focus on Helping Individuals Live a Self-Directed Life").

A critical step of the self-direction process is executed via choices for budget allocations. The NJ Division of Developmental Disabilities (DDD) determines individual budgets based on each individual's needs and a weighted factor for acute medical, behavioral, and self-care needs. The amounts are grouped into tiers and restricted by the state's finite resources.

Most importantly, budgets for long-term services and supports must be economically sufficient to support the person of very low-income. It can be particularly challenging for individuals in Tiers A and B on the Supports Program or the Community Care Program to have sufficient resources to live independently. At present, artificial budget categories prevent moving unspent funds to other line items that align with the person's priorities and where funds are needed. Regulations with more flexibility would permit the individuals to utilize all of the funds allocated to their budgets. A review of this system would identify needed updates.

Recommendations:

- ✓ Continue to promote self-direction, self-advocacy and self-determination for individuals with I/DD.
- ✓ Review funding system and regulations for needed updates.
- ✓ Review the tier budgets for individuals and rate setting for vendors and establish a mechanism for ongoing updates to assure that sufficient funds are available to support individuals with I/DD.
- ✓ Provide line item flexibility within individual budgets so that funds can be fully utilized for approved services.

References:

- Walker, Pam, et al. "Policy Research Brief: Implementation of Consumer-Directed Services for Persons With Intellectual or Developmental Disabilities: A National Study." *Research and Training Center on Community Living, Institute on Community Integration*, vol. 20, no. 1, Jan. 2009, <https://ici.umn.edu/products/prb/201/default.html>.
- Bailey, Caitlin, and Corey Gilden. "Barriers and Catalysts to Self-Directed Services and Supports for Adults with Disabilities." *Optum, United Health Group*, 2018, https://cdn-aem.optum.com/content/dam/optum3/optum/en/resources/publications/Final_IDD_Provider_Survey_on_Self-Directed_Services_and_Supports_Report.pdf.
- "A Focus on Helping Individuals Live a Self-Directed Life." *Optum*, 2017, <https://www.optum.com/content/dam/optum3/optum/en/resources/PDFs/spark-overview.pdf>.

“Self-Directed Services.” *The Centers for Medicare & Medicaid Services*,

<https://www.medicaid.gov/medicaid/ltss/self-directed/index.html>. Accessed 8 Dec. 2018.

3. Microboards™ Support Individuals with Planning, Advocacy, and Plan Implementation over a Person's Lifespan.

A Microboard™ is a small (micro) group of committed family and friends who join together with the individual to create a non-profit board. This board assists the person with a disability to plan and achieve one's goals. Often the board monitors and advocates for what is needed (*Vela Canada*).

Parents, relatives, and friends can serve essential roles in advocating, planning, and executing Person-Centered Planning. For example, for those with significant cognitive, behavioral, or medical issues, relatives who know the person best may interpret their non-verbal communication to help guide the person-centered process and assist in directing services. In preparation for when family supports may no longer be an option, these natural supports can be expanded to a more formalized Microboard™. Incorporated as a legal non-profit, these entities advocate, plan, implement, and monitor the PCP with the individual.

In Canada, more than one thousand people use Microboards™ to accept funding, support decision making, and seek services and solutions when problems arise (*Vela Canada*). Integration within one's community is a guiding principle and forms the basis of the support system. In multiple locations, including Canada, Virginia, Tennessee, and Illinois, Microboard™ trade associations provide technical assistance to those interested in establishing one (*Virginia Microboard Association*; “Tennessee Association of Microboards and Human Service Co-Ops”).

Recommendations:

- ✓ Develop options for support when families can no longer assist individuals with planning, decision-making, and self-direction.
- ✓ Explore options to utilize Microboards™ to support individuals in planning and decision-making.
- ✓ Provide technical assistance to individuals and families regarding Microboards™.

References:

Vela Canada. <https://www.velacanada.org/>. Accessed 8 Dec. 2018.

“Tennessee Association of Microboards and Human Service Co-Ops.” *Tennessee Council on Developmental Disabilities*, <https://www.tn.gov/cdd/projects-and-initiatives/community-supports-and-services/microboards-and-human-service-co-ops.html>. Accessed 8 Dec. 2018.

Virginia Microboard Association. <http://virginiamicroboards.org/>. Accessed 8 Dec. 2018.

4. Support Coordination and Support Brokerage Assist Individuals with Person-Centered Planning to Attain Life Goals.

Support Coordination: A service that assists a person to gain access to needed services, including state plan services, programs, and individual supports. The Support Coordinator is the person responsible for developing the Individualized Service Plan.

Support Brokerage: Supports Brokerage is a broadly defined activity, designed to help the individual manage their individual budget and to locate, arrange for, and manage the services they need. The Support Broker serves as a navigator, linking the person to both natural community supports and/or to funded services, in accordance with the individual's Person-Centered Plan and individual budget (*NJ DDD Supports Program Policies and Procedures Manual Version 4.0*).

Effective Support Coordination is essential to the development of Person-Centered Planning and Implementation and establishes a foundation for self-direction. It differs from the traditional model of case management of matching the person to available resources. Support Coordination empowers the individual to seek the resources that lead to achieving life goals (Gettings et al.)

The strong role of Support Coordination calls for a high caliber of personnel and commensurate funding rates for services along with manageable caseloads so that Support Coordinators can be responsive to overall and critical needs (Moseley). The system requirements to collect and analyze data should be delegated to other personnel so that Support Coordinators can keep their focus upon the individual with I/DD.

Support Coordinators may not possess the specialized knowledge required to obtain particular resources such as locating affordable housing. In this case, employing a Support Broker with specific expertise may be beneficial. Additionally, when natural supports or families are not available to assist individuals to secure services and supports, professional expertise may be necessary. States such as Pennsylvania utilize Support Brokers, as a Medicaid Waiver billable service, for this purpose. The New York Housing Resource Center (HRC) for People with Intellectual/Developmental Disabilities, formerly known as NYSACRA, offers extensive training to "Housing Navigators" who are experts at designing and locating housing options (*New York Housing Resource Center*). While New Jersey has a service definition for the assistance of a Support Broker, that service is currently underutilized and poorly understood, and the reimbursement rate is low. Individuals and their families need additional information regarding support brokerage and how to utilize this service option.

Self-directed services and individual budgets increase consumer choice, resulting in increased service provider accountability. Self-determination includes decision-making about where to live and work and with whom to live, as well as all other decisions affecting his or her life. Individuals have the right to make choices and control decisions in their lives to the fullest extent that they are able.

Recommendations:

- ✓ Empower individuals through choice, self-direction, and individual budgets, resulting in person-centeredness and provider accountability.
- ✓ Manage Support Coordinator workloads to have small caseloads and limited administrative responsibilities so that focus is primarily upon individual and not system needs; delegate data collection and quality assurance monitoring responsibilities to other entities.
- ✓ Address the low supply of Support Brokers by establishing a viable reimbursement rate for these providers, so that families may access this specialized service.
- ✓ Educate individuals and their families about the service option of support brokerage.
- ✓ Utilize Support Brokers with specific knowledge to research and secure necessary services when the family or the individual with I/DD is not able to do so independently.

References:

Moseley, Charles R. *Support Brokerage Issues in Self-Directed Services*. July 2004, p. 13.

Gettings, Robert, et al. *The Case for Medicaid Self-Direction: A White Paper on Research, Practice, and Policy Opportunities*. National Council on Disability, 22 May 2013,

https://ncd.gov/rawmedia_repository/23720a02_e755_42f4_b366_dff166ba0c96.pdf.

New York Housing Resource Center. <https://nyhrc.org/index.php>. Accessed 8 Dec. 2018.

5. Coordinated Healthcare and Wellness Education Is Easily Accessible

Health Homes: In Medicaid-funded Health Homes, providers integrate and coordinate all primary, acute, behavioral health, and long-term services and supports to treat the whole person

People with developmental disabilities may have complex medical and behavioral health care requirements. Many people with disabilities are unable to communicate their medical symptoms. Health care practitioners must spend additional time to listen, examine, and evaluate the person's medical care needs. The Medicaid reimbursement rates for primary care are low and provide no incentive for medical practitioners to address the complex needs of this population. The individual may see several specialists and take multiple medications that need coordination. In the absence of well-coordinated health care, individuals rely upon costly and inefficient care within emergency rooms or in-patient hospitalizations.

Individuals with I/DD and their paid caregivers may not be well educated about the symptoms of a variety of illnesses or know how to respond. For some individuals, their limited self-awareness or inability to communicate may pose additional obstacles when seeking care. Gaining a better understanding of the treatment plan development assures better follow through on implementation. Many could also benefit from education about how to lead a healthy lifestyle.

Having well-coordinated medical care and wellness educational services can improve health, reduce medical costs, increase longevity, and enhance quality of life. Service Providers for people with mental health issues or homelessness have recognized the importance of providing primary care close to where people live. The principles of a "medical home" include easy access to primary care that focuses upon treating the whole person. Care managers coordinate care and address the medical health, behavioral health and social factors affecting the person's life. Collaboration among all providers is critical to successful outcomes. In Chicago, a Managed Care Organization, called the Medical Home Network, demonstrated success on many levels when implementing this patient-centered medical home concept in community-based settings ("Proven Model").

Under the Hospital Partnership Subsidy Pilot Program, New Jersey's Housing and Mortgage Finance Agency (HMFA) will match funding contributions from participating hospitals to provide much-needed housing for low and moderate-income families. The developments also must include units set aside for residents with special needs and/or individuals who frequently use hospital emergency room services. Studies have shown that permanent supportive housing can improve the quality of life and health of frequent emergency room users as well as help hospitals save on emergency room costs ("NJHMFA Seeking Hospitals Interested in \$12M Supportive Housing Partnership").

In addition, HMFA will be providing incentives to projects that provide health and wellness services to senior affordable housing projects in the 2019/20 applications for Low-Income Housing Tax Credits. Affiliations with hospitals and health care entities will assure access to medical care. A nurse will be available onsite to supply wellness services. Social services coordinators will link people to mainstream resources.

According to the Corporation for Supportive Housing's (CSH) report, *Best Practices for Serving Aging Tenants in Supportive Housing*, inpatient hospitalizations decreased by 92% when instituting primary medical care and social service supports within a homeless population in Brooklyn ("Supportive Housing"). New York State has established a Medicaid Redesign Team with a supportive housing priority to institute several pilot programs of new models of care ("Redesigning New York's Medicaid Program").

Recommendations:

- ✓ Implement the "Healthy Homes and Medical Homes" concepts that offer a combination of primary healthcare and wellness services incorporated into residential settings or neighborhoods for individuals with developmental disabilities.

References:

Crabtree, Benjamin F., et al. "Summary of the National Demonstration Project and Recommendations for the Patient-Centered Medical Home." *The Annals of Family Medicine*, vol. 8, no. Suppl 1, May 2010, pp. S80–90. www.annfammed.org, doi:[10.1370/afm.1107](https://doi.org/10.1370/afm.1107).

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6. Options Incorporating Best Practices Are Available to Meet the Intensive Support Needs of Those with High Acuity

People with the most significant disabilities often experience the most challenge in attaining appropriate supports. For example, individuals with complex behavioral and/or medical challenges may need highly specialized services. These families may face increased stress, pain, and injury caused by issues such as aggression, self-injury, elopement, and other behavioral challenges, and frequent hospitalizations. Identifying appropriate and accessible experts, interacting with direct support professionals, and accessing long-term treatment that is sensitive to the dynamic nature of medical and behavioral challenges may prove to be very challenging. The costs and design of their supports may not align with the typical scope of services. When approval of the decisions for their care requires a higher level of authority, a team with the necessary expertise and authority to make decisions should be available to expedite this process.

More supportive service options are needed for those with intensive medical or behavioral health care requirements. Innovative residential models need to be developed to address these needs in inclusive settings whenever possible. These models should be designed for safety and incorporate experienced clinical teams that can provide treatment for the existing medical and behavioral needs of the residents. New Jersey’s current Community Care Program may prove to be the best option to provide sufficient funding, increased opportunities, and personalized planning for those requiring intensive, specialized supports.

A Robert Wood Johnson Foundation initiative, THE GREEN HOUSE® Project Model, provides elders of low income with high-quality, personalized care within small home settings. A Green House home differs from a traditional nursing home in terms of facility size, homelike interior design, organizational structure, staffing patterns, and methods of delivering skilled, professional services. Models for individuals with developmental disabilities and intensive medical care needs could benefit from inclusion in such health home concepts (“The Green House Project”).

Recommendations:

- ✓ Develop innovative models to safely treat the intensive medical and/or behavioral health needs of individuals with I/DD.
- ✓ Develop an urgent response system with a team of experts who are empowered to make decisions and access available supports when a person with complex needs has an emergency need for residential services.

References:

Barth, Sarah, et al. “State Trends and Innovations in Medicaid Long-Term Services and Supports.”

Center for Health Care Strategies, 1 Dec. 2012, <https://www.chcs.org/resource/state-trends-and-innovations-in-medicare-long-term-services-and-supports/>.

Ensslin, Brianna, and Alexandra Kruse. “State Trends in the Delivery of Medicaid Long-Term Services and Supports.” *Center for Health Care Strategies*, July 2016, p. 14.

“The Green House Project: Reimagining Traditional Nursing Homes.” *Robert Wood Johnson Foundation*, <https://www.rwjf.org/en/how-we-work/grants-explorer/featured-programs/the-green-house-project.html>. Accessed 8 Dec. 2018.

7. The System is Invested in a Strong Direct Support Workforce.

Direct Support Professionals (DSP’s): DSPs are paid caregivers who provide support and assistance to individuals with disabilities, in or out of the individuals’ homes, so that the individual can achieve or maintain increased independence, productivity, enriched social experiences, self-determination, and inclusion in their community. The tasks performed by a DSP can vary widely, ranging from simple to complex, as outlined in the individual’s service plan.

Successful outcomes for persons with I/DD rely heavily upon the quality of the direct service personnel supporting them. Longevity and consistency of caregivers are essential to their well-being. Demographics indicate that as more baby-boomers are retiring, the availability of workers is diminishing. Currently, the rate of unemployment is low. As people are living longer and needing more in-home services requiring paid personnel, the shortage of workers is further exacerbated. The availability of direct support professionals is vital to the continuation of individualized residential models.

Increased wages, flexibility in scheduling, and increased training towards a professional career path, all enhance the role of the DSP. The University of Minnesota's Institute on Community Integration conducts research and provides leadership on best practices concerning the workforce serving people with I/DD through their publications ("Impact"). With broad input from stakeholders, New York's Workforce Investment Program makes \$245 million available through waiver funding for initiatives to retrain, recruit, and retain healthcare workers ("Managed Long Term Care Workforce Investment Program").

When individuals and their families wish to hire workers to provide individual assistance and personal care, they may require aid and a large network for recruitment. Systems are needed to locate workers, often on short notice. In California, Virginia and New York, <http://www.Mysupport.com> provides personal profiles to match individuals needing supports to direct support personnel. Investment to supply a well-prepared direct support workforce is critical to the quality of care for individuals with I/DD ("MySupport").

An emerging best practice in London, called the Key Ring model, impacts the DSP workforce shortage ("What We Do: Network Model"). Individuals with disabilities live in scattered homes in close proximity to paid DSP and volunteers in the same neighborhood. This model enables a DSP to share their time with several people simultaneously and additional personnel are available to be called when needed. Volunteers offer natural supports and assistance reducing reliance upon paid staff.

Recommendations:

- ✓ Continue to advocate for increased wages for direct support personnel.
- ✓ Establish a career path for the DSP workforce.
- ✓ Promote incentives for DSPs including education, training, and increased credentials.
- ✓ Establish mechanisms for recruitment of personnel to work as direct support employees.

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8. Technology, Including Smart Home Technology, Universal Design Advance Independence, and Reducing Reliance upon Personal Assistance

Assistive Technology Device: An assistive technology device is an item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of participants (*NJ DDD Supports Program Policies and Procedures Manual Version 4.0*).

Smart Home Technology: This refers to devices that can be installed in a person’s home to make home operations easier and/or safer, and that are often activated by easy-to-use, wall-mounted buttons, voice commands, or wireless remote. Examples include power door openers, emergency notification systems, motion sensors, thermostat controls, automatic shut-off devices, video monitoring, etc.

Assistive Technology Service: Assistive technology service means a service that directly assists a participant in the selection, acquisition, or use of an assistive technology device.

Universal Design: Universal design is the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. The intent of the universal concept is simply life for everyone by making more housing usable by more people at little or no extra cost (*Universal Design in Housing*).

In countless ways, technology has become a function in our everyday lives. In our homes, these applications can keep us safe, provide us more independence, control comfort, and offer convenience in our homes.

Some people with physical or intellectual disabilities can accomplish many tasks without assistance from others because of technology. Smart home technology can be customized to supply personalized assistance designed to achieve certain outcomes. In these ways, technology can assist some individuals to live more independently.

Video monitoring and communication devices within their homes provide an individual with assistance as needed. Cost savings, efficiencies, and increased independence can be achieved through this adaptation. Medication administration can be facilitated by systems that prompt, record administration, or notify a third party, when needed. Safety features can detect when a person has been in the bathroom too long, taken a fall, or left the home. Applications can also identify who is at the front door or can shut off the stove if unattended. Personal Emergency Response units automatically summon help in the event of a problem. Homes can be designed

with smart home features that can be customized for each resident. Technology specialists, as well as occupational therapists, with an understanding of the needs of people with I/DD, are developing individual plans to incorporate technology into the homes to support safety and independence. *SimplyHome* technology experts report that several states experienced significant cost reductions with the use of assistive technology. Their website testimonials attest to these cost savings (“Case Studies”).

The State of Ohio deems itself a "Technology First State" and utilizes assistive technology to provide more independence for people with disabilities (“Technology First”). Ohio and several other states rely upon video monitoring to reduce reliance upon direct support personnel for some individuals with I/DD.

Issues that must be considered when deciding upon assistive technology include choice, security of personal information, and protection of privacy as more communication occurs between devices inside and outside of the home. Coleman Institute for Cognitive Disabilities promulgated a "Declaration on the Rights of People with Cognitive Disabilities to Technology and Information Access" providing a statement of principles on the rights of all people to inclusion and choice in relation to technology and information access (“Declaration on the Rights of People with Cognitive Disabilities to Technology and Information Access”).

Advances in smart home technology should be considered for inclusion as features in Universal Design for housing construction. Universal design considers human needs and abilities throughout the lifespan. It specifies the elements to be incorporated into housing that can accommodate all people, especially those with challenges related to aging or physical limitations. Many adaptations support people so they can “age in place.” These modifications are not very costly, and people of all ages can benefit from them. For example, bathroom grab bars assist someone of any age who has limited balance or ambulation difficulties. People of all ages use ramps, lifts, and elevators to ambulate up stairs. Universal design attributes should include a list of essential features that promote accessibility for aging in place as well as technological advances. Incentives and enhanced requirements for developers will result in construction of homes that accommodate people who are elderly or have physical and/or intellectual disabilities.

Recommendations:

- ✓ Publish a database of experts in technology who can consult and plan individually for persons with I/DD to achieve personal objectives for independence.
- ✓ Establish reasonable guidelines that protect safety and privacy when using technology in licensed and unlicensed facilities.
- ✓ Incorporate revised universal design features into building standards, providing reasonable accommodations for accessibility, aging in place, and smart home technology.
- ✓ Require housing developers to incorporate revised universal housing design features into all new government funded projects.
- ✓ Develop incentives to build aging in place and smart home technology adaptations into a percentage of all new construction sites.
- ✓ Promote funding for modifications to existing housing stock to facilitate the needs of people as they age or become physically disabled.

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9. Community Integration is Fostered When Designing Housing and Supports.

Community Integration: Individuals are fully included when they are full participants and contributors in their schools, workplaces, churches, and the broader community. Community Integration results in mutual respect and richer, more meaningful relationships between a person with a disability and those without disabilities.

Preferred lifestyles for many individuals with disabilities involve living in small, personalized settings with opportunities to lead integrated lives in his or her community. Their neighborhoods provide easy access to services, shopping, recreation, places of worship, and transportation. People with disabilities want to cultivate friendships and develop meaningful relationships. A variety of residential models and settings facilitate such inclusion.

The Kelsey has developed multifamily housing apartments in downtown San Jose to be fully inclusive of people with and without disabilities in urban settings. Intentionally designed to promote community, their residents represent people of mixed abilities and incomes ("The Kelsey Ayer Station").

Award-winning Gardant Management Solutions offers assisted-living inclusive of individuals with I/DD as well as supported living serving people of all income levels, including those relying upon Medicaid (“Community Types”).

Knowledgeable Support Coordinators, families, and professionals can facilitate the development of innovative residential service models that enhance an individual's opportunities for full inclusion.

The Centers for Medicare and Medicaid Services (CMS) funds residential supports through Home and Community-Based Services (HCBS) Waivers. CMS requires a Statewide Transition Plan, which describes how the state will assure compliance with the Americans with Disabilities Act so that all funded services are provided in the most integrated settings appropriate for the person. New Jersey's plan calls for an evaluation of all licensed facilities to determine the level of community integration afforded to each person. A survey has been developed to review the opportunities that a person has to live an integrated life. All residential settings will be evaluated to assure that residents have opportunities to interact and develop relationships outside of the residence.

On a related note, while some people define “community integration” as interaction with the community-at-large, others prefer to more narrowly define the community of which they wish to be a part and may do so for a variety of reasons and needs. To address these preferences and needs, intentional communities are an option within the continuum of residential settings. Well-designed intentional communities can offer access to both a smaller, planned community and the community-at-large while providing a greater sense of belonging with meaningful social interaction. Regarding acute clinical needs, some individuals and their parents favor the safety and design of a specialized setting because those with severe medical and behavioral challenges may require access to specialized treatment 24 hours per day that is not easily accommodated in small residential settings. For example, an individual with medical challenges may need high levels of nursing care. Similarly, individuals with behavioral challenges sometimes pose significant risks to themselves and others, requiring accommodations. Consistent with the intent of ADA and CMS regulations, the community integration survey mentioned above will play a critical role in determining if intentional communities and more specialized settings are offering the greatest amount of community integration possible.

Integrated housing development may include small numbers of people with disabilities to reside in a single location among housing for people without disabilities. Several models support this concept. For instance, apartment complexes constructed with Low-Income Housing Tax Credits provide incentives for 25% of the housing units to be "set-aside" for people with special housing needs. Additionally, co-housing is an integrated, planned community for people living together with a common philosophy of caring for one another. Typically, community members reside in their own homes or apartments in close proximity to one another. This "village" can be located in a variety of settings, sizes, and configurations. Community gatherings are commonplace with formal and informal activities to bring people together on a regular basis to share meals and activities. Friendships develop among neighbors. Shared supports are exchanged among the residents based upon each person's talents and abilities. People with disabilities contribute as well as receive support (“What Is Cohousing?”).

Another variation of this concept involves Co-ops. Cooperative ventures can offer lasting residential supports with a high degree of involvement among family members. An organization in Massachusetts, Cooperatives for Human Services, helps families to establish these collaborative ventures (“Cooperative Homes”). Often, friends desire to live together and their families decide to pool their resources to make this model work. Each individual and their family agree to contribute time and resources to support the people with disabilities who live together.

Shared living is another model of pairing compatible people who share housing, as well as financial and household, responsibilities. This model can include live-in housemates and/or other people with disabilities living in the same household. It is optimal for the person with the disability to hold a lease (preferable a master lease) so that as caregivers change, the person with the disability retains his/her home (Wehrlen).

Many states, for instance Massachusetts, New Hampshire, Georgia, Texas, and Pennsylvania, offer host homes also known as Adult Foster Care, Teaching Family Homes, Lifesharing, or Providership Homes. This concept is cost effective and proves most successful when careful matches are made between the family and the resident. The best scenario exists when the host family has the support and resources of a provider agency for respite, training, crisis intervention, and quality monitoring.

Many states are reducing their reliance upon group homes or reserving those beds for people with the most intensive needs. Smaller capacity, with fewer than four people, is preferred. Parents want stability and continuity in housing and care giving. Some describe how their son or daughter had to vacate their homes when his or her behavior became disruptive or service providers changed. To address this concern, New Jersey has been advancing the approach of a separation of housing ownership from supportive services. The person with I/DD has the stability of a consistent home when disruptions occur and they can choose their caregivers/service provider and housemates. In instances where families have the resources, some families have chosen to purchase a home or condominium to control the place where their relative lives. Often, the deed to the home names a legal entity such an LLC or special needs trust as the owner.

Recommendations:

- ✓ Encourage development of new housing and supportive service models that incorporate community integration into the design.
- ✓ Educate individuals, families, and professionals, especially Support Coordinators, regarding additional housing models, including co-housing, co-ops, and shared-living that promote community integration.
- ✓ Supply technical assistance for those developing supported housing models that promote integrated community.
- ✓ Test and determine the efficacy of the NJ State Transition Plan's survey tool in evaluating the quality of community integration across the full continuum of residential options.
- ✓ Expand capacity by encouraging family purchasing of housing for integrated housing models such as shared living and co-ops.

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10. Build the Capacity of Affordable Housing through Funding Housing Development and Rental Assistance

Affordable Housing: Affordable housing represents public and private sector efforts that assist people with low and moderate-income to lease or purchase housing.

Rental Assistance: Rental assistance refers to subsidies administered through state, county, or local government to assist people with low or moderate-incomes to lease housing.

Individual choice and self-direction are exceptional concepts as long as there are options from which to choose. Housing development must be affordable and readily available. A statewide assessment of special needs housing would supply valuable information to support legislative initiatives to expand the capacity of affordable housing. Such a study of special needs should assess not only the number of people requiring housing, but also the geographic areas desired and the type of supportive services required. (see Section 12, *Research and Data Analysis Drive Planning and Policy Decision-Making*).

It is well known that people with special housing needs require both rental assistance and supportive services. The availability of these funds must occur simultaneously in order for people with I/DD to access affordable housing when it is available. Currently, New Jersey residents juggle multiple funding sources with varying means of access. Housing developers fear that units will go vacant if people cannot afford to pay the rent.

New Jersey Division of Developmental Disabilities (DDD) has adopted the principle of separating housing from supports. Fewer DDD service provider agencies engage in housing development, preferring instead to rent apartments or single-family homes. Housing developers and service providers must coordinate their efforts to provide for effective service delivery.

NJHMFA's Qualified Allocation Plans (QAP) for Low-Income Housing Tax Credits specify the areas of service delivery that housing developers must fulfill to score projects in the competitive funding process for these funds. Other state agencies such as DDD and the Department of Community Affairs (DCA) could make funding opportunities and determinations simultaneously with housing development. This type of "triple play" would assure that people could access affordable housing, rental assistance, and supportive services simultaneously and thus be successful in developing their person-centered plans for living as independently as possible.

New sources of funding for housing development, particularly in settings that facilitate integrated residential models, are essential to the future of affordable housing for people with I/DD. The NJ Special Needs Housing Trust was effective in offering developers funding and flexibility to establish community housing for those with I/DD. Currently, that fund is depleted. Advocacy could encourage the New Jersey legislature to allocate additional monies to replenish the essential capital funds for special needs development. The Housing and Community Development Network of NJ recommends in *Thrive New Jersey* that Governor Murphy and legislative leaders restore \$600 million annually into a strategic set of housing and community investments ("Thrive New Jersey").

In 2016, California enacted legislation called "No Place Like Home," dedicating up to \$2 billion in bond proceeds to invest in the development of permanent, supportive housing. The bonds are repaid by funding from the Mental Health Services Act (MHSA). Key features of the program include that funded counties must commit to provide mental health services and help coordinate access to other community-based supportive services. Vulnerable populations are offered flexible, voluntary, and individualized supportive services ("No Place Like Home Program").

Several states encourage families to donate homes for their relatives. In California, the Lanterman Housing Alliance works with families to develop "Legacy Homes" ("Legacy Homes") In Wisconsin, an agency, Movin' Out, supplies technical assistance to families establishing a residence for their relative. Connecticut has the "Home of Your Own" program ("Disabled Persons Homeownership Mortgage Program"; "Access to Homeownership for People with Disabilities and Their Families in Wisconsin").

Recommendations:

- ✓ Replenish the NJ Special Needs Housing Trust Fund or other dedicated funding to provide funding for affordable housing development.
- ✓ Seek funding for the development of additional affordable housing, rental assistance, and supportive services

- ✓ Fund a combination of support available simultaneously for affordable housing development, along with rental assistance vouchers and supportive housing services, to address the population with special needs.
- ✓ Promote family-donated housing to provide additional, permanent, sustainable housing.

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11. Simplify Ease of Access and Referral to Service Delivery

No Wrong Door: The No Wrong Door approach provides individuals with a universal gateway to community services and government programs. It enables clients with expeditious access to eligibility and services (“No Wrong Door”).

The ways of accessing the current systems for supportive housing and services are complex. Governmental entities at all levels administer their systems with little coordination between agencies, thereby unintentionally creating "silos." Multiple contacts and applications are required, causing inefficiencies for all involved along with confusion and discouragement for consumers and their families. Ease of access could improve by use of a single, coordinated, and simplified intake and application process. One common application could serve multiple purposes among agencies; cross training among agencies' intake personnel would promote efficiency and ease implementation of the "No Wrong Door" concept. The principles of "No

Wrong Door" can apply to a streamlined process to access publicly funded housing and supportive services.

As an example, when seeking a HUD rental assistance voucher, a plethora of public housing authorities administer rental vouchers in New Jersey. A person has to apply individually to these locations. Each agency accepts an application through its own process and maintains its own waiting list. In Massachusetts, ninety-nine local housing authorities utilize one preliminary application and maintain one computerized waiting list for rental assistance vouchers. Each authority establishes its own priorities and criteria. All housing authorities consider applicants, however, for all subsidies for which they qualify through this one single, common application ("Section 8 Housing Choice Voucher Program").

On a local level, the New Jersey towns of Princeton and Hopewell have instituted something similar. Completing one application, a person can request rental-assistance and affordable housing from all various sources in their towns.

Nationally, there is a huge demand but a dearth of available rental subsidies. In New Jersey, DDD is providing state funding to subsidize the rent of its constituents until federal assistance is available to its constituents. Such an interim supplement is essential. As noted in the previous section, supported housing advocates must lobby for increases in federal funds so that people with low-incomes can afford housing.

For a person with I/DD to live independent of their family's home, affordable housing with rental assistance and supportive services must be available simultaneously. To live near family members and people who provide natural support is a great benefit for a person moving to independence. Possible residences can be anywhere in the state and can include higher income areas. Locating housing vacancies in desirable neighborhoods that are willing to accept Fair Market Rents can be a challenge. The US Department of Housing and Urban Development (HUD) published the [Small Area Fair Market Rents \(SAFMR\) Final Rule](#) pertaining to its Housing Choice Vouchers (*Small Area Fair Market Rents*). It establishes payment standards to calculate Fair Market Rates (FMRs) in high rent neighborhoods according to specific ZIP codes rather than larger geographic areas. The intent is to increase allowable rental subsidies in desirable locations with low poverty. DDD could utilize these SAFMR in determining the allowable rents for its voucher program and increase access to those locations as well. This would allow a person with I/DD to utilize their voucher closest to their circle of support.

A comprehensive system is required so that potential tenants can be well-informed of available, affordable housing units. Assistance from Brokers who have dual expertise of the housing market and the individualized needs of individuals with I/DD is needed until a more effective system is developed.

Apartment complexes constructed with federal Low-Income Housing Tax Credit funding must "set-aside" or designate a percentage of housing units for people with special needs. However, provisions state that the apartment may be rented to the general population, if available special needs apartments are not leased in a timely way. People with I/DD should not lose out on these opportunities. Better coordination must occur between property owners and consumers,

support coordinators, and service providers. Large housing developers may not know how to seek referrals for their vacancies. A better notification of apartment availability and a stronger referral system could help. Developers should also affiliate directly with service providers or link to support coordinators to inform them of available rental units.

Similarly, the DDD referral processes for agency-directed supports are fragmented. Providers must market their services directly to potential consumers. Individuals with individual budgets must research placement opportunities. Licensed community residences sustain vacancies while individuals wanting such services remain waiting. Again, to avoid opportunities lost, a better communication system is needed between providers and individuals when residential openings exist. Individuals should be permitted to add their names to waiting lists to move quickly when vacancies occur.

Those self-directing also need assistance finding compatible housemates and service providers. Organizations like the National Shared Housing Resource Center collect profiles and offer potential matches for people seeking shared-living arrangements (“Why Shared Housing?”).

Assessments prior to expansion should identify service needs, geographical preferences, and housing models of interest. Service providers and housing developers expect that once a vacancy is available, there will be people ready for occupancy, i.e. with housing assistance vouchers in hand and funding for supportive services secured. Effective communication and referral systems could make this happen.

Recommendation:

- ✓ Implement a No Wrong Door approach to intake and eligibility across funding systems.
- ✓ Cross train professionals about other services beyond their particular area of expertise to accommodate a No Wrong Door approach.
- ✓ Simplify the application process to a common application to apply for supportive services, housing, and rental assistance vouchers simultaneously.
- ✓ Advocate for additional HUD funded rental assistance and continue to provide DHS/DDD rental assistance until individuals can secure them.
- ✓ Utilize Small Area Fair Market Rates when determining DHS rental subsidies for specific locations.
- ✓ Develop an effective referral system to match people to available affordable housing options.
- ✓ Design a coordinated referral system to match up the availability of vacancies within DDD waiver services for those on the waiting list.

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12. Research and Data Analysis Drive Planning and Policy Decision-Making

Outcome Measure: An outcome measure is the result of a test that is used to objectively determine the baseline function of a patient at the beginning of treatment. Once treatment has commenced, the same instrument can be used to determine progress and treatment efficacy (*NJ DDD Supports Program Policies and Procedures Manual Version 4.0*).

Too often, governmental services are over-regulated and not focused on outcome-based data. Service providers complete volumes of paperwork that have little relevance to the quality of the service delivery. Additional inspection processes often are instituted as an over-reaction to a tragic event. Regulations overlay additional reporting and oversight. Millions of dollars are spent each year to implement these oversight laws with no quantifiable outcome for the investment. Alternatively, resources could be better utilized to drive continuous, quality improvement by instituting a coordinated system of quality review. Such efforts should be evaluated to determine their effectiveness in preventing harm and achieving positive outcomes for consumers. Best practices would promote efficacy-based approaches grounded upon the collection and analysis of data. The Quality Mall at <http://www.qualitymall.org> offers access to resources (“Person-Centered Services Supporting People with Developmental Disabilities”).

The Council on Quality and Leadership advocates for using measureable outcomes and data when evaluating quality or making decisions. The Council on Quality and Leadership (CQL) publishes Personal Outcome Measures[®] based upon twenty-one indicators, to evaluate if services and supports are person-centered. Individuals as well as providers and government agencies can use the information surveyed to measure quality of life and effectiveness of service delivery. CQL also provides a toolkit for states to use for a detailed review of quality measurement based upon CMS requirements (“Toolkit For States”).

A Policy Research Brief by the University of Minnesota's Research and Training Center on Community Living reviews available research on the costs and outcomes of community service provision for people with I/DD, with a particular emphasis on residential services. The review focuses on a number of key issues related not only to public expenditures, but also to funding systems, related policies and regulations, and their impact on service systems, specific service types, and service-users (Stancliffe and Lakin). At both the state regulatory and the service provider administration levels, data can be evaluated and utilized for improving quality.

In addition to the need for analysis on quality of service and delivery, current studies and assessments based on the need for affordable housing do not include special needs housing. As a result little data exists on need or preferences for people with I/DD. As noted in Section 10, *Build the Capacity of Affordable Housing through Funding Housing Development and Rental Assistance*, a statewide assessment of special needs housing would supply valuable information to support legislative initiatives to expand the capacity of affordable housing. Such a study of special needs should assess not only the number of people requiring housing, but also the geographic areas desired, housing models of interest and the type of supportive services required. Future expansion should rely on this data driven foundation.

A needs assessment should be conducted to identify service needs, geographical preferences, and housing models of interest and utilized as the foundation for planning future expansion.

Recommendation:

- ✓ Designate funding for data scientists to identify, collect and analyze data to report outcomes and benchmarks by which future progress can be measured.
- ✓ Use research and objective data to drive decision-making and policy development.
- ✓ Conduct a needs assessment to identify service needs, geographical preferences and desired housing models to plan future expansion.
- ✓ Allocate resources to expand funding, models, settings and housing development based upon assessment of needs and preferences.

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Summary:

In conclusion, New Jersey has already adopted many national best practices that benefit individuals with I/DD. Many recommendations have been made in this report to expand upon, as well as implement, additional initiatives. Best practices articulated in this report represent successful initiatives in other states. They warrant further consideration regarding their applicability and likelihood for success in New Jersey. SHANJ in collaboration with its partners will continue to advocate for implementation of best practices into service delivery systems.

Note: The opinions articulated in this report do not necessarily reflect those of the NJ Council on Developmental Disabilities, who funded this project.

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