

**Recommendations to
Improve the
Health and Safety of
Individuals with Intellectual and
Developmental Disabilities
Who Receive Services from the
New Jersey Division of
Developmental Disabilities**

**A White Paper developed by the Health and Safety
Subcommittee (HSS) of the New Jersey Regional
Family Support Planning Councils (RFSPC)**

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The Health and Safety Subcommittee (HSS) of the New Jersey Regional Family Support Planning Councils (RFSPC) is comprised of 10 regional councils representing all 21 counties in New Jersey. The RFSPCs were created in 1993 as authorized by the New Jersey Family Support Act. More information about the RFSPCs can be found at <https://njcdd.org/the-regional-family-support-planning-councils/>. The subcommittee is comprised of 15 RFSPC family member advocates for individuals with intellectual/developmental disabilities (IDD) receiving services by the New Jersey Division of Developmental Disabilities (DDD) who live in residential placements and/or participate in other community settings such as day programs.

These family advocates formed the HSS in recognition of the lack of health and safety oversight after a family whose daughter passed away while living in a provider managed home as the result of a series of unaddressed common health issues for individuals with IDD. The subcommittee acknowledges the dedication of these families and the New Jersey Council on Developmental Disabilities in the creation of this document. It is the expectation of the HSS subcommittee that DDD, provider agencies and direct support professionals (DSPs) will partner with us in the review of the following recommendations based on both literature and personal experiences of families to make system changes to incorporate the oversight, accountability and transparency needed to maintain safe, healthy and meaningful lives of the individuals with I/DD within their care.

Based on its own description:

“The Division of Developmental Disabilities (DDD) enables adults with intellectual and developmental disabilities (I/DD) to live, work and participate meaningfully in their communities. Through partnerships with individuals, families, and service providers, we continually strike a balance between our core goals of ensuring health and safety while supporting and respecting the rights of individuals to make their own choices (<https://www.nj.gov/humanservices/ddd/about/division/>).”

Mission:

Create a partnership that includes families, the Department of Human Services (DHS), DDD providers and identified advocates to construct a system of services and supports with appropriate oversight, transparency and accountability designed to guide and foster quality health and safety outcomes for individuals with I/DD and co-occurring medical conditions.

Introduction:

With the core goal of ensuring health and safety, DDD is challenged by the complexity of care required for people with I/DD receiving services in their community settings. Often these challenges not only include I/DD but co-morbidities associated with a wide variety of medical diagnoses and behavioral challenges. Co-occurring diagnoses for individuals with I/DD served by DDD include autism spectrum disorder (12.9%), cerebral palsy (11.4%), epilepsy (19.2%), Down syndrome (5.2%), and encephalopathy (2.6%) along with a myriad of other diagnoses (19.8%) that require specific healthcare oversight for known comorbid conditions (see Background: Appendix 2). This challenge requires added levels of healthcare oversight by caregivers who have enhanced knowledge from required targeted training. Without appropriate training that affords caregivers the ability to meet this challenge; poor health outcomes and tragedies can and have been experienced.

Individuals with I/DD with co-occurring medical issues require added levels of healthcare oversight to remain healthy and safe. Inconsistency in the quality of care results in poor overall health outcomes and in some cases, death. The lack of required standardized trainings and utilization of best practice curriculums, professional oversight, and transparency contributes to poor quality and outcomes. Co-occurring health conditions in these individuals often complicate the ability of many providers and caregivers to recognize, report and react to emerging or current medical conditions that in many cases can be managed with proper training and medically-focused guidelines (see Background: Appendix 2).

While partnerships between families, individuals and providers are crucial to better health outcomes, families frequently encounter resistance to their involvement. There is a growing body of evidence acknowledging the importance of a family-centered care approach for adults with chronic conditions including those whose care is delivered within family homes and community-based settings. For adults with chronic conditions, patient and family-centered care involves providing opportunities for the individual, provider, and family to work together toward good health outcomes as defined by the individual and/or their family.

“Families participate in care most effectively when policies and procedures support their role. For families whose loved one lives outside of the family home, this means having reliable and comprehensive services and supports as needed, flexible visiting hours and accessible facilities. Family voices are also critical in policy and program development. Families offer critical perspectives necessary for systems level change ranging from legislation to the policies and procedures of facilities and medical providers, to the education of service providers. For example, Title V Maternal and Child Health programs actively involve the voices of family partners in program development and evaluation, peer supports, and policies. Families may need supports to actively participate in these processes.” (See Background: Appendix 2)

This theme is noted within some of the HSS recommendations. The subcommittee hopes DDD and providers will join us in acknowledging the important role families and close advocates of the individual play in the health and safety of those who have been entrusted in their care.

The following recommendations for system change were drafted by the HSS with the intention to significantly improve the health and lives of individuals with I/DD in licensed community settings. While some recommendations may potentially result in increased costs in specific areas, such as caregiver training, these recommendations will ultimately lower overall system costs as **evidence suggests that the associated cost savings from reduced emergency room visits, hospitalizations, medications, medical appointments and procedures would result in lower overall system costs associated with superior life outcomes** (see Background: Appendix 2).

Presented in this document are Short Term Goals which the HSS have identified as requiring immediate attention and/or can be achieved relatively quickly. These goals include, but are not limited to, a review of relevant division circulars to make them consistent with current best practices and changes to NJCA 10:44A that relate to operational policies and procedures associated with health and safety. Additionally, long Term Goals are under discussion by the Health and Safety Subcommittee.

This White Paper is a blueprint for anticipated improvement in the delivery of supports and services across New Jersey. HSS welcomes initial and ongoing input, feedback and comments by email: NJHSSWP@gmail.com.

Short-term Target Areas and Recommendations

In accordance with NJ Department of Human Services (DHS) Division of Developmental Disabilities: Division Circular 1, family members must be included in the development and review of all operational policies and procedures associated with health and safety. Family input is critical in all circulars and licensing standards used to oversee health-related procedures and supports, including mandatory training, medication administration records (MARs), other related record keeping, access to healthcare in a variety of settings (in-person, telehealth, etc.), nutrition, and exercise as deemed necessary to meet the person-centered support needs of each individual (for example within: NJAC 10, 10:41, and 10:44A).

1. Improve positive health outcomes for individuals receiving provider managed supports and services within licensed and unlicensed settings.

Recommendations:

- a. Require more robust healthcare training and certification for Direct Support Professionals (DSPs) and management personnel in settings that provide Individual Supports (CCP), Community Based Supports (SP) and Day Habilitation (CCP and SP), utilizing existing and available teaching curricula. One example of such healthcare training can be reviewed here: <https://hrstonline.com/hrsu/the-fatal-five-fundamentals/>. Certification programs for DSPs are available through the College of Direct Supports and other certificate programs. These certificate programs should be a requirement for DSPs. Post-completion competency should be assessed intermittently to insure knowledge is continually integrated in the service setting.
- b. Ensure all staff (residential and day program), DSPs and supplementary staff, have been trained to meet the support needs of each individual they are serving in a person-centered manner. Require and document staff have reviewed the current Person Centered Planning Tool (PCPT) and Individual Service Plan (ISP) for each individual under their care prior to providing supports. Additionally, staff responsible for the supports of an individual with a completed the Addressing Enhanced Needs form (AEN) must document they have reviewed the AEN.
- c. Require Support Coordinator (SC) to work with the individual with I/DD (when possible), family members, or an alternate advocate in preparing the AEN “Addressing Enhanced Needs” form to address medically-related needs supported by physician/practitioner

documentation. In the absence of a family member or appointed guardian, determine if there is an advocate who is familiar with the healthcare needs/supports of the person with I/DD who is able to assist in completing documents such as ISP & PCPT and/or approval process (referred to as “advocate” in remainder of this document). Require that a copy of the AEN form be distributed to the family/guardian upon completion. Based on the Tier Assignment and Acuity Factor, ISP, PCPT and AEN forms (Available at: <https://www.nj.gov/humanservices/ddd/documents/addressing-enhanced-needs.pdf>), the SC and Provider Performance and Monitoring Unit (PPMU) should monitor for compliance in meeting the enhanced needs of the individual. Provider hiring of specially trained personnel to include but not limited to Registered Nurses (RN), Licensed Practical Nurses (LPN) and Board Certified Behavioral Analysts (BCBA), should be required, based upon the enhanced needs of the individual. Office of Program Integrity and Accountability (OPIA) visits should monitor for compliance to ensure enhanced services needs have been documented and met for the individual.

- d. Restructure the ISP & PCPT to include a section regarding essential healthcare needs for all individuals who require clinical monitoring of daily bodily functions (e.g., fluid intake/output, bowel movements, blood glucose levels, etc.) or other medically-related needs, such as special dietary needs and/or as supported with physician/practitioner documentation. The ISP/PCPT will be completed by family members or guardians who are knowledgeable about the needed daily oversight related to health and safety and reviewed by the SC. The completed ISP/PCPT will be shared with the provider to develop a plan to address identified healthcare monitoring and oversight. The Plan must include a monitoring tool (chart) to record the execution of daily healthcare needs identified in the ISP/PCPT to be completed by staff as recommended in the ISP/PCPT. Family member/guardian/advocate and individual should review and approve the provider plan. Family member/appointed guardian/ advocate, individual, SC and providers/DSPs will sign off on the final approved documents. If no other advocate is identified, the Plan should reflect whether an advocate should be identified through the Ombudsman, Disability Rights New Jersey or another source.
- e. In the case of a newly emerging health issue(s), the Provider must alert the SC in order that the ISP/PCPT be updated within 3 calendar days. The update must include how the

provider will implement the new plan with approval by family member/guardian/advocate (see Sections 1c & d).

- f. Implement guidelines designed to assist staff in optimizing health and safety for **all** individuals with I/DD living in a licensed setting, using the National Core Indicators (NCI) generator as a model. Develop a tool based on factors identified in the currently approved ISP/PCPT for use by staff to record the individual's daily care plan, modified during a medical event and the recuperation period. The tool should include documentation of medical visits for routine checkups/procedures and required follow-up visits, specific individual health concerns, diet/nutrition, weight management (Body Mass Index), physical activity/strength exercises, etc. in a person-centered manner.
- g. Review, develop and implement staff training that focuses on education and resources to meet the nutritional needs of the individual. Training should include general food safety/handling and nutrition, as well as specific trainings related to special diets as identified within an individual's ISP/PCPT, e.g., diabetic or ketogenic diets.
- h. Require SC to review all enhanced health service needs, as documented in the PCPT, ISP and AEN, are being met as part of monthly monitoring with the individual and/or their family/guardian/advocate and the provider. In the absence of a family member or appointed guardian, the previously identified representative will participate in the meeting (see Section 1c).
- i. Medication Administration Record (MAR) documentation and health-specific protocols must require specific training and monitoring of DSPs and supervisors must be responsible for the implementation of these activities in a person-centered manner. Medical Administration Records should be available to family members to verify accurate medication administration, use of pre-packaged medications and related health protocols. Designing protocols to ensure correct administration of medication.

2. Ensure health and safety oversight through external monitoring.

Recommendations:

- a. OPIA should make reports of DD qualified service provider oversight within publicly available documents. OPIA should contact family member/guardian/advocate especially when OPIA discovers any reportable conditions. The family member/guardian/advocate

should be able to contact OPIA to alert OPIA of a concern health and safety related issue to request it be explored at the next unannounced visit.

- b. Oversight by a government entity or independent contractor of the performance of DDD service providers is imperative. Oversight should be focused on the ability of providers to fulfill person-centered services as required in the Supports Program and Community Care Program. Family/guardian/advocate and provider representatives should be members of the oversight committee.
- c. A dashboard should be available within the DDD qualified provider database that provides meaningful insight into provider performance (e.g., include data on meeting medical/dental appointments, engaging in identified community activities as specified in ISP/PCPT, etc.) to ensure that individuals/families/guardians are able to make informed choices.
- d. Electronic monitoring and other assistive technology should be options available to individuals/families/guardians/advocates in meeting the individual needs within the ISP and PCPT.
- e. Managed Care data should be included to provide a baseline and trends to facilitate measurements and comparisons of health outcomes.
- f. Managed Care providers should further explore ways in which access to healthcare can be delivered to individuals with I/DD such as telemedicine. The Centers for Medicare and Medicaid (CMS) has expanded the use of telemedicine and encourages states to consider telehealth options to facilitate clinically appropriate care and deliver covered services available under Medicaid.

3. Electronic Health Records and daily record keeping of required services must be maintained by the provider and be available to families/guardians.

Recommendations:

- a. DDD must set a standard for service monitoring that is clear and consistent throughout the provider community. The monitoring system employed must be transferrable to any other agency serving that individual.
- b. Providers only use systems or apps that allow for the transfer of records.
- c. Providers must maintain documentation that is consistent with and incorporates person-centered measures based on the individual's needs as outlined in the ISP and PCPT.

- d. Outcome measures for ISPs and PCPTs must be monitored by oversight agencies and Support Coordination with individual and family/guardian/advocate input.
- e. Individual person-centered support needs must guide the documentation in order to protect the health and safety of the individual. Examples include monitoring of daily input and output, blood sugar levels, caloric intake, etc. (see Recommendation 1).

4. Improve outcomes through provider collaboration with individuals and their families ensuring provider acceptance of family input, visitation and involvement.

Recommendations:

- a. Providers must provide individuals and families/guardians with their policy and procedure manual that include and encourage the input of both individuals and families/guardians in the service model.
- b. Team meetings with the individual, family/guardian/advocate, and SC, should take place annually to update and discuss implementation and oversight to verify that person-centered needs as specified in the ISP, PCPT and on the AEF form are being met. The provider should also be invited to the meeting to ensure continuity between all partners including family/guardian/advocate, individual, and SC. Additional joint meetings should be convened to allow discussion of any new issue(s) that impact on health and safety, as needed and requested by the individual and family/guardian/advocate and/or the SC (see Recommendation 1, Sections b-e, h).
- c. Procedures must be clearly made available, mandated and implemented to ensure provider collaboration with families, provider recognition of family input, guarantee of family visitation rights and family involvement in their loved ones' lives.
- d. Providers must set policies in spirit and practice that strictly prohibit any retaliation by the provider when a complaint is filed by the family/guardian/advocate or individual. DDD must immediately act on reports of retaliation through an external process that protects the rights of individuals and their families/guardians.
- e. Require licensed providers to annually update family/guardian/advocate contact information and share with other families with a member sharing the residence and/or participating in a day program for those who desire this information. Documentation required annually to confirm family/guardian/advocate has/has not consented to share contact information with other families and noted in the ISP/PCPT.

5. Protect and prevent individuals from repeat abuse, neglect and/or exploitation.

Recommendations:

- a. While current statutes restrict access to documents and findings pertaining to an investigation in order to provide protection of others involved, individuals and their families/guardians must be allowed to participate, contribute and have timely/prompt access to investigations and reports.
- b. While current statutes restrict access, the Office of Program Integrity and Accountability (OPIA) must be given statutory ability to revise its policies and procedures related to investigations to provide the greatest level of protection of all individuals it serves while ensuring individuals/families and guardians have reasonable access to documents related to an investigation (see Recommendation 5a).
- c. Agencies must be required to have nonaffiliated family members on their Human Rights Committees and require nonaffiliated family members to be participants in the internal investigation team.
- d. OPIA should include neutral nonaffiliated family members in investigations and inspections whenever possible.

6. DDD must provide a platform for an independent person to mediate and resolve issues between providers, individuals and their families and guardians.

Recommendations:

- a. DDD has a duty to establish a process to mediate and resolve issues between providers and families. Since the state and federal government pay for services, families feel they lack leverage to influence providers, especially when there are limited options available within the provider network.
- b. Disability Rights New Jersey or an independent authority outside of DHS is required to mediate and resolve issues and grievances involving families and providers. Only the active participation and support of government service funders can ensure that families can approach and interact with providers as equals.

Appendix 1. Background

The New Jersey system that serves individuals with intellectual/developmental disabilities (I/DD) who live in various residential settings managed by providers is primarily funded through state and federal Medicaid dollars. Although Medicaid funding is a healthcare benefit, the NJ Division of Developmental Disabilities (DDD) and NJ Children's System of Care (CSOC) system lack specific and effective guidelines to meet comprehensive healthcare needs of individuals with I/DD using a person-centered approach. The lack of meaningful person-centered effective guidelines and oversight has resulted in the deterioration of the health of many individuals with I/DD living in various residential settings in NJ. For this paper, adults with I/DD served in the DDD system will be the focus.

Many individuals with I/DD have multiple complicating factors that present significant challenges for staff in recognizing early signs of illness. Some individuals with I/DD experience a range of communication barriers, such as cognitive impairments, limited speech, or complete inability to speak, that impact directly on their ability to effectively relay subtle changes in their physical well-being. This added layer of complexity requires caregivers to be well trained in a multitude of areas and have a clear understating of compounding factors unique to each individual, e.g., communication skills, level of cognitive functioning, chronic and past medical concerns, to ensure their health and well-being. It is critical the caregiver is trained and able to implement the care required for each individual according to their person-centered plan.

Co-existing issues for people with I/DD require a wide-range of person-centered support needs ranging from mobility impairments necessitating adaptive equipment (e.g., walker, wheelchair, ramps, shower chair, etc.) sometimes in combination with both long-term and short-term medical interventions (e.g., physical, occupational and speech therapy, etc.), hearing impairment, and inability to communicate verbally with a need for an augmentative speech device. These co-occurring health conditions often complicate the ability of caregivers to recognize, report and react to emerging or current medical conditions. The inability to effectively communicate discomfort or pain to a staff member, whether due to lack of speech or cognitive impairment, and absence of person-centered plans has exacerbated failures to recognize emerging medical issues in need of medical intervention.

Mortality data indicate that without person-centered training and oversight it is likely that this subset of the I/DD population is at higher risk for premature/preventable death (See References: Appendix 2). Except for a very limited number of medical groups and healthcare systems experienced in addressing health issues for people with I/DD, the general health service system is ill-equipped to recognize and address the medical needs of this vulnerable group. Morbidity studies have documented numerous health concerns that when diagnosed and treated at an early stage regularly lead to positive outcomes within the general population. Unfortunately, these same health concerns, occur more frequently within the I/DD population, often go unrecognized and untreated, and lead to more serious consequences, including death.

Physical symptoms of common medical issues (e.g., constipation, discomfort on urination, dehydration, toothache) coupled with limited or no communication skills and/or cognitive barriers can lead to and have directly resulted in severe negative health outcomes for individuals with I/DD. It is widely recognized that a significantly higher proportion of people with I/DD experience several common medical conditions than the overall population and have been linked to an increased incidence of poor health outcomes, including death. This group of common medical conditions, often referred to as the Fatal Five (now 6 identified) include:

1. Aspiration
2. Constipation/Bowel Obstruction
3. Dehydration
4. GERD
5. Seizures
6. Infection/sepsis

Person-centered medical training targeted to teach staff to prevent, recognize and effectively manage these health conditions has been shown to improve daily care and health outcomes for individuals with I/DD. Healthcare training focused on how to recognize specific medical conditions at an early stage allow caregivers to respond appropriately, potentially avoiding a more serious negative health outcome. Over the past decade, the recognition that people with I/DD are susceptible to the “Fatal Five” has led to programs designed to address and educate staff about the signs and symptoms of each of these commonly known medical issues. Additionally, person-centered training of caregivers is effective in recognizing the early signs of illness in those they support, resulting in better outcomes.

While DSPs during a normal shift provide a wide range of supports from transportation, personal care and medication administration and much more, the ability to recognize emerging healthcare issues is absolutely vital at every support level. Direct care services for individuals with I/DD living in licensed facilities are funded by Medicaid. Clearly, individuals who require these services and supports to live in their communities need staff who have received formal healthcare training, and in some cases, certification and continuing education. Appropriate training curricula are readily available, accessible, and can be adapted to the meet specific person-centered training for each individual with I/DD at every level of support needs.

Most individuals with I/DD have been cared for in their family home for most of their lives. Generally, families have been intimately involved at every level of care and have a wealth of knowledge about their family member’s needs, most importantly, medically-related care oversight. Families should be allowed and encouraged to convey that knowledge to caregivers in licensed facilities, where DSPs may have little or no experience caring for these vulnerable individuals. Families are the “experts” about the individual and should be able to provide person-centered details about daily care as well as common signs and signals of potential medical conditions to which they may be susceptible. This knowledge and experience is critical for those persons with co-occurring personal challenges, e.g., limited or no communication skills, cognitive impairments, etc. This subgroup is at increased risk for developing medical conditions that if not recognized and addressed appropriately will worsen and may result in devastating negative health outcomes.

Despite the wealth of person-centered information and knowledge families can provide to staff, especially medically-related conditions, families frequently report providers are often not receptive to family involvement, including health-related concerns. Partnerships between families, individuals and providers are crucial to better health outcomes. This lack of collaboration has often led to poor overall health of individuals with I/DD resulting in avoidable medical conditions, including hospitalizations with serious health outcomes, even death.

In New Jersey, adults with I/DD needing and receiving services within DDD are required to complete the NJ Comprehensive Assessment Tool (NJ CAT). This tool is a needs-based assessment survey that is intended to measure support needs and is used to develop the ISP and PCPT. Results of the

NJ CAT establish each individual's tier and budget used to pay for required supports. The ISP is meant to reflect the level of support, including specific person-centered thinking and planning tools needed to keep the individual healthy & safe (medical & behavioral), and staff qualifications including training requirements to support the individual.

Appendix 2. References

Co-occurring health and safety references

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<https://disabilitycompendium.org/compendium/2019-state-report-for-county-level-data-prevalence/NJ>

<https://drexel.edu/~media/Files/autismoutcomes/publications/NAIR%20Health%202020.ashx>

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