NASDDDS

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Report to North Dakota

Eligibility, Service Array and Person-Centered Practices: *Observations and Recommendations for Consideration*

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Background and Methodology

Through the Centers for Medicare & Medicaid Services (CMS) Home and Community Based Services (HCBS) Technical Assistance (TA) project, the National Association of State Directors of Developmental Disabilities Services (NASDDDS) has worked with North Dakota to review the State's service delivery system for long-term services and supports. Specifically, the TA engagement entailed:

1. Conducting a comprehensive review of the state's existing waiver programs to identify potential paths for eligibility for non-I/DD eligible individuals. This review will entail gap identification with programmatic recommendations for consideration to address areas requiring programmatic bolstering;
2. Provide the state with strategies to improve (and maintain) consistency in the application of criteria across staff responsible for applying eligibility criteria.
3. Assist the state in identifying potential strategies to address gaps in service, including those to support individuals with co-occurring MH/IDD needs.
4. Provide information and recommend tools/strategies to the state related to person-centered practices and planning.

In addition, the TA included providing the state advice on strategies to identify and/or mitigate conflict of interest in case management structures (not addressed in this report but provided during the course of the work with the state).

The TA team worked with a cross-agency group of North Dakota state staff to gather background information on eligibility standards, methodologies and procedures, service arrays across programs and person-centered planning approaches. This effort, combined with two statewide virtual (via interactive webinar) stakeholder meetings and a survey distributed by the state to a wide array of stakeholders, provided the foundation for the observations and recommendations for consideration contained in this report.

Medicaid Systems for Long Term Services and Supports

In North Dakota, as in most states, Medicaid is a significant source of long-term supports and services (LTSS). Medicaid, including all state plan benefits and all waiver programs, forms the basis for the LTSS system for individuals with disabilities and individuals who are aging. In FY 2015, North Dakota spent $586,059,000 on LTSS, with 42.1% of those dollars spent on community-based services.[1]

[1] Eiken, S; Sredl, K; Burwell, B. Medicaid Expenditures for Long-Term Services and Supports (LTSS) in FY 2015 April 14, 2017

The community-based LTSS system in North Dakota consists of Medicaid state plan benefits, such as personal care, as well as an array of Home and Community Based Services (HCBS) waiver programs for individuals with particular conditions meeting an institutional level of care (nursing facility, intermediate care facility for individuals with intellectual and developmental disabilities and hospital). In addition, it is notable that the LTSS system in North Dakota is significantly augmented by state-funded programs, including the Service Payments for the Elderly and Disabled (SPED) and the Expanded Service Payments for the Elderly and Disabled (ExSPED) programs.

Eligibility practices across Target Populations

Within Federal guidelines, each state establishes an applicable level of care criteria for each institutional setting. States apply these criteria when individuals are admitted to the applicable institution, but, importantly, the criteria also apply for individuals who are seeking to receive services in a 1915(c) HCBS waiver program, which offers services as an alternative to institutionalization. In addition to the criteria used, states often devise their own procedures, required assessments and other practices to ascertain whether an individual meets the applicable level of care. These practices determine clinical eligibility for the program in question, and couple with financial eligibility determination to ensure that the individual meets the applicable means testing necessary for the Medicaid program.

Medicaid authorities

The Medicaid program is set forth in Title XIX of the Social Security Act. The program consists of mandatory eligibility groups and mandatory services, as well as an array of optional benefits. States may cover optional benefits under the Medicaid state plan as well as through available waiver programs. Most of the LTSS benefits are optional, including State Plan personal care and all home and community-based services. HCBS waivers are designed for particular target groups so the availability of services in any given state may vary based on the program design decisions made by the state, including types, amounts and scopes of services available by target group.

North Dakota, as all states, recognizes the importance of having a rich array of benefits available to support individuals with disabilities and individuals who are aging in an array of settings, including their homes and communities. The state's outreach for TA reflects an ongoing commitment to continually evaluating their systems to ensure that it is accessible and that it meets the needs of individuals who require LTSS.

NASDDDS Approach to Technical Assistance

As noted above, NASDDDS has engaged in ongoing discussions with state staff, has reviewed a multitude of state statutes, regulations, policies, tools and process descriptions to gain an understanding of the comprehensive North Dakota service delivery system. After review of all of these materials, in addition to the valuable interactions with state staff and stakeholders (including self-advocates, family members, advocates and providers), NASDDDS offers the following observations on the North Dakota system of support and potential areas for consideration for the state to make improvements in the areas noted above.

Eligibility

Eligibility Practices Across Target Populations

In most states (as in North Dakota) eligibility criteria and processes for determination of eligibility vary across the populations served. For seniors eligibility may focus on health and daily living skills, for individuals with physical disabilities the focus may be similar to that for seniors with sometimes added focus on personal care. For individuals with I/DD, the focus may be on a combination of cognitive and functional abilities. Children's system eligibility also relies on distinct criteria and assessment tools that are specific to the age of the applicant. Using different criteria and methods to assess eligibility for children and adults as done in North Dakota is the national norm.

A few states have moved to a more "universal" approach to eligibility utilizing a core functional assessment plus some population-specific criteria and assessments. As an example, Wisconsin uses the Functional Screen, which has adult and children's versions.[2] This screen has core elements that are the same plus population-specific questions. Minnesota has the most comprehensive universal assessment, which is used for their fee-for-service and managed care systems.[3] But, like Wisconsin, Minnesota has population-specific screens including developmental disability screening, long-term care consultation assessment, personal care assistance assessment, and a home care nursing assessment to be included in the future.

Supports for Individuals with ID/DD, Eligibility For Intellectual/Developmental Disabilities Services, Developmental Disabilities Case Management Services

Eligibility for entrance into the North Dakota system of services for individuals with I/DD begins with establishing eligibility for Developmental Disabilities Program Management (DDPM). DDPM is North Dakota's case management system for individuals with I/DD. Program financing is claimed as a Medicaid administrative expense. DDPM is provided through the Regional Human Service Centers, which are under the umbrella of the Department of Human Services. DDPM provides information, referral, and support to eligible individuals so they access needed services. The DDPM (DDP Manager) also completes intake, service authorization, person-centered service plan development and on-going monitoring. North Dakota's eligibility criteria follow most other states which typically require the individual to have an intellectual and/or developmental disability—including related conditions. The eligibility criteria includes

[2] https://www.dhs.wisconsin.gov/functionalscreen/index.htm
[3] https://mn.gov/dhs/partners-and-providers/news-initiatives-reports-workgroups/long-term-services-and-supports/mnchoices/

individuals with intellectual disabilities [mental retardation]who do not meet the functional criteria to also have a developmental disability, but are able to "benefit from treatment and services".

DDPM eligibility for individuals 3 and older is based on criteria established under ND Administrative Code 75-04-06 and references NDCC 25-01.2, the developmental disabilities definition. NDAC 75-04-06 establishes three sets of criteria under which an individual age 3 or older can qualify for DDPM:
1. …the individual has a diagnosis of mental retardation which is severe enough to constitute a developmental disability.….
2. … the individual has a condition of mental retardation… which is not severe enough to constitute a developmental disability, and the individual must be able to benefit from treatment and services purchased through the developmental disability division on behalf of an individual who meets the criteria of subsection 1.
3. … the individual has a condition, other than mental illness, severe enough to constitute a developmental disability, which results in impairment of general intellectual functioning or adaptive behavior similar to that of an individual with the condition of mental retardation, and the individual must be able to benefit from services and intervention techniques which are so closely related to those applied to an individual with the condition of mental retardation that provision is appropriate.
North Dakota Code 25-01.2 defines developmental disability using the federal definition of developmental disability with the addition of specifically citing Down Syndrome as a developmental disability.[4] To ascertain eligibility a variety of documentation and assessment tools are used to make the eligibility determination. These documents are reviewed by a team composed of at least three professionals from the regional human service center and is led by the developmental disabilities program administrator or the administrator's designee.

Eligibility for infants and toddlers is found in NDAC 75-04-06 which states:

a. Developmentally delayed means a child, from birth through age two:
    (1) Who is performing twenty five percent below age norms in two or more of the seven areas
    (2) Who is performing at fifty percent below age norms in one or more of five areas
b. High risk
    (1) Who based, on a diagnosed physical or mental condition has a high probability of becoming developmentally delayed; or
    (2) Who, based on informed clinical opinion, which is documented by qualitative, and quantitative evaluation information, has a high probability of becoming developmentally delayed.
    (3)

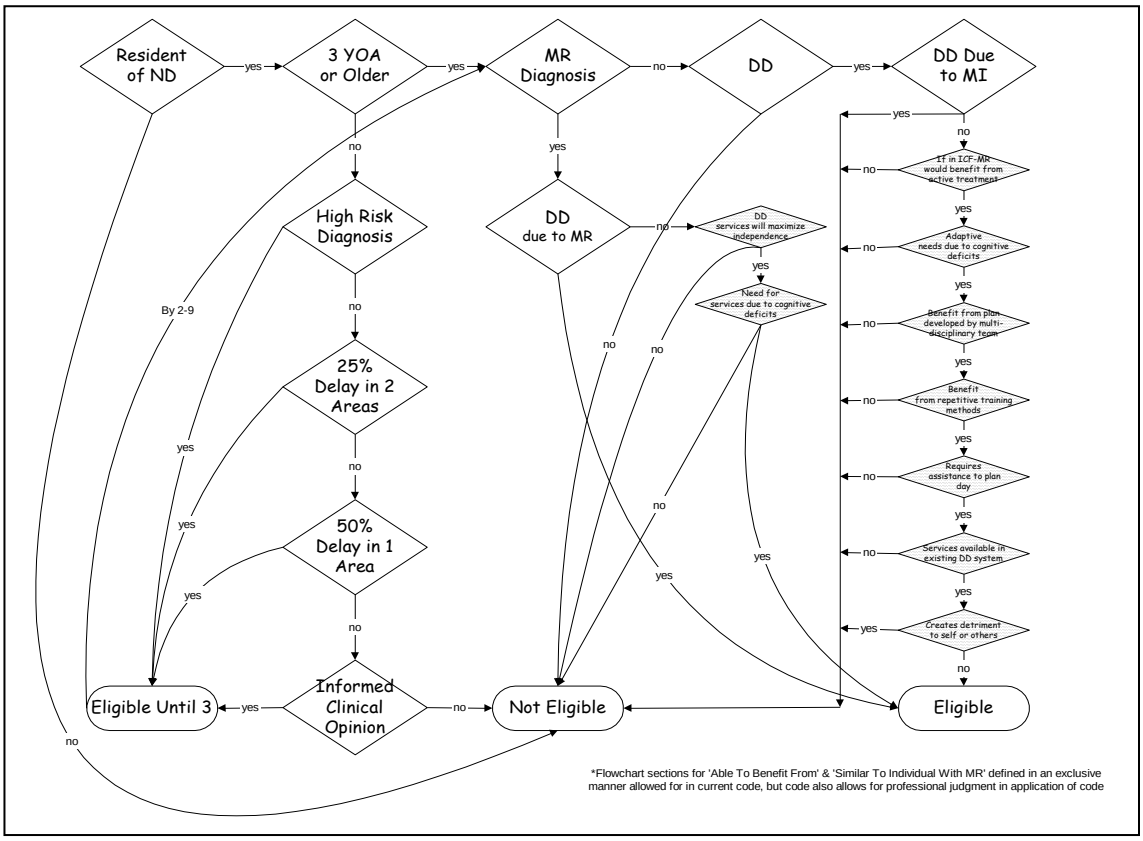
The determination is made by the team of professionals using a hierarchy that looks at multiple factors:

1. High risk for developmental delay
2. Performing at 25 % below age norms in two or more of seven areas
3. Performing at 50% below age norms in one or more of five areas

[4] ND Code 25-01.2: http://www.legis.nd.gov/cencode/t25c01-2.pdf
Federal definition of DD: http://www.mscdd.org/definition-of-developmental-disabilities/

4. Informed clinical opinion by the early intervention professional team.

The eligibility determination allows the use of any assessment that shows a percentage delay. In addition, a multi-disciplinary evaluation in five domains must be completed for the 25%, 50% and Informed Clinical opinion areas.



Eligibility Criteria and Determination Processes: Issues and Recommendations

Issue: "…not severe enough to constitute a developmental disability"
The language in the regulation (for age-adults) seems more complex than it might need to be. Most states just indicate categorical eligibility such as a diagnosis of intellectual disability (often specifying the I.Q. "cut-off" for eligibility) and/or functional eligibility, i.e., a developmental disability (including related conditions). The "not severe enough" eligibility language reportedly may have led to confusion around eligibility. Some states do require that all individuals they serve must have an intellectual disability to qualify for services, but most states allow for individuals with developmental disabilities (and related conditions) to qualify without regard to intellectual disability as long as the functional limitations, age of onset and a need for services

similar to those provided to individuals with ID/DD are met. (See below for discussion on eligibility for individuals without intellectual disability.)

Recommendation: North Dakota could establish a clearer category perhaps just stating as many states do, the individual for purposes of eligibility must have an intellectual disability, and/or a developmental disability. Valid and reliable assessments that demonstrate the individual has an intellectual or development disability is all that is required for eligibility. The next step is the functional (and other) assessment to ascertain the need for supports and services are needed. Basically having an intellectual and/or developmental disability gets you through the eligibility door to the next determination which is an assessment of need for services.

In terms of eligibility based on related conditions, the process is the same. You can do a screening to initially ascertain if the individual meets the definition of related conditions. The second step is the assessment of functional status and support needs. You may want to establish certain diagnoses or conditions as related conditions as well as assessing functional limitations and establishing the age of onset. (See below for more information.)

The suggestion is to clarify that an individual may have an intellectual disability, and/or a developmental disability and/or a related condition, and meet eligibility for your system. The second step is assessments to further establish documentation of eligibility and ascertain support needs.

Related Conditions
42 CFR 435.1009

"… severe, chronic disability that meets all of the following conditions and is attributable to:
(1) cerebral palsy or epilepsy or, (2) any other condition, other than mental illness, found to be closely related to mental retardation [sic] because this condition results in impairment of general intellectual functioning or adaptive behavior similar to that of mentally retarded [sic] and requires treatment or services similar to those required for these persons, (b) it is manifested before the person reaches the age of 22, (c) it is likely to continue indefinitely (d) and results in substantial functional limitations in three or more of the following areas of major life activities: (1) self care; (2) understanding and use of language; (3) learning; (4) mobility; (5) self direction; (6) capacity for independent living."

Issue: Related conditions

Related conditions are defined in federal regulations at 42 CFR 435.1009. The definition of related condition is primarily functional, rather than diagnostic, but the underlying cause must have been manifested before age 22 and be likely to continue indefinitely. Related conditions have included developmental disabilities which are defined in P.L. 101-496.

How states choose to assess for and define related conditions varies. Some states do use the functional definition while others explicitly specify a list of conditions such as autism, epilepsy and cerebral palsy that meet the related condition criteria. Two studies on state eligibility practices indicate more usage of some type of functional assessment tool to ascertain if the individual has a developmental disability. The tools states use include nationally validated tools such as the ICAP, DDP, InterRAI, and the SIS. [5] Some states have developed their own tools including the Wisconsin Functional Screen, California CDER, Ohio OEDI/COEDI, Washington (see appendix ?? for a resources on these tools.) By using a consistent process, states are better

[5] SEE: Zaharia, Ric, *Report to the Maryland Developmental Disability Administration: A Review of the Eligibility Determination Process*, July 25, 2016, and Moseley, Charles and Zaharia, Ric, *"State Strategies for Determining Eligibility and Level of Care for ICF/MR and Waiver Program Participants"*, Rutgers, July 2008

able to assure eligibility is determined in the same manner across the state. A number of questions arose about how to ascertain if the individual qualifies as having a related condition:

- Should an individual with Borderline ID be considered as a related condition (even if there are no other diagnoses?

Recommendation: In terms of assessing related conditions, the question may not be the severity of an intellectual disability, but the person's functional status—and the age of onset of the limitations. So, an individual with borderline ID could meet related conditions *if* they have functional limitations *and* require treatment or supports similar to those provided to individuals with ID.

- What approach should be used to determine when the person's diagnosis would be considered a related condition, especially if the diagnosis is something that is not common?

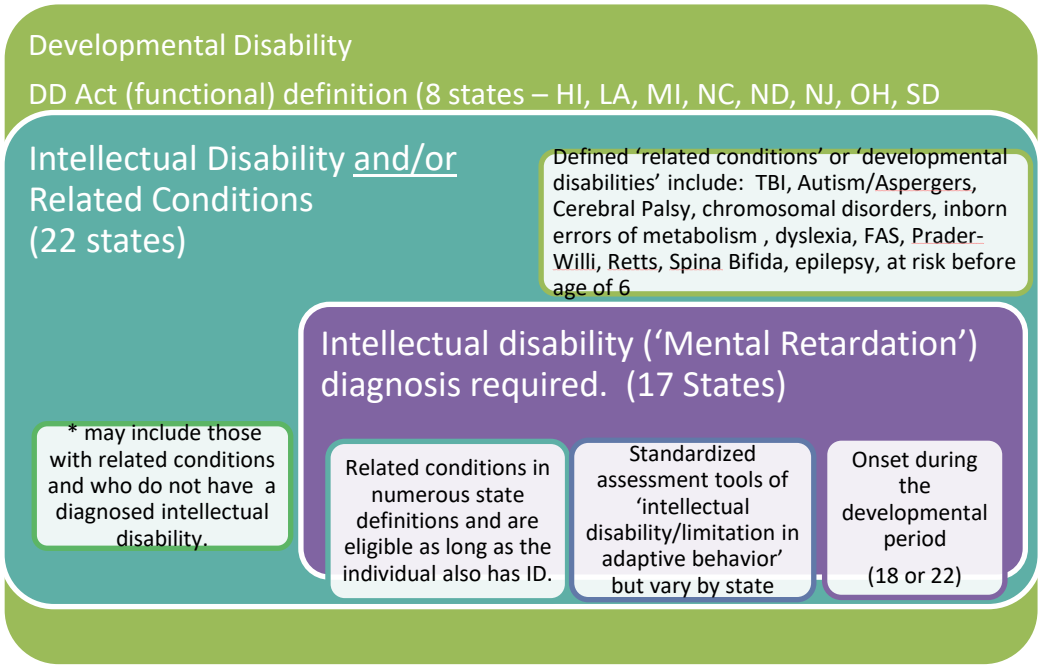
Recommendation: Most states do not ascertain related conditions eligibility using exhaustive diagnoses lists. States do specify a few diagnoses as meeting related conditions as can be seen from the chart. Moseley and Zaharia also reported that, "twenty-one (21) states reported using "other" diagnostic categories to determine eligibility. Additional conditions covered by states include: dyslexia (AR), autistic disorder (ME), Retts (MA), specific learning disability (NH), familial dysautonomia (NY), deaf-blind with multiple disabilities (TX), and tuberous sclerosis (WV). The majority of states do have a catch all eligibility criterion that establishes that persons are eligible who have closely related conditions with impairments in major life activities without specifying the condition."[6]

Moseley, Charles and Zaharia, Ric, *"State Strategies for Determining Eligibility and Level of Care for ICF/MR and Waiver Program Participants"*, Rutgers, July 2008, p.6

Table 1: Diagnoses Reported by the States for Admission into State and Waiver Programs Diagnostic Criteria	Mental Retardation and Related Conditions	Developmental Disability
Mental Retardation, Cognitive or Intellectual Disability	AL, CT, IA, MA, ME, MN, NE, NV, OK, PA, TN, TX, UT, VA, VT, WY	AK, AR, AZ, CA, CO, DC, DE, FL, GA, HI, ID, IL, IN, KS, KY, LA, MI, MO, MS, MT, NC, ND, NH, NJ, NM, NY, OH, OR, SD, WA, WV
Cerebral Palsy	NV, PA, TX, UT, WY	AK, AR, AZ, CA, CO, DC. FL, GA, ID, IL, IN, KS, LA, MI, MO, MT, ND, NM, NH, NJ, NY, OH, OR, SD, WA
Epilepsy	PA, TX, UT, WY	AK, AR, AZ, CA, CO, DC, FL, GA, ID, IL, IN, KS, LA, MI, MO, MT, ND, NH, NJ, NM, NY, OH, SD, WA
Prader-Willi Syndrome	CT, NV, TX, UT WY	AK, DC, DE, FL, GA, IN, KS, LA, MO, MI, MS, ND, NJ, NY, OH, OR,
Autism	MA, ME, PA, TX, UT, WY	AK, AR, AZ, CA, CO, DC, DE, FL, GA, ID, IN, KS, MI, MO, MS, MT, ND, NH, NJ, NM, NY, OH, OR, SD, WA, WV
Autism Spectrum	MA, NV, TX, UT, WY	CO, GA, IN, KS, LA, MI, MO, ND, NJ, OH, OR, SD,
Asperger's Syndrome	MA, NV, TX, WY	DE, GA, IN, LA, MI, MO, ND, NJ, NM, OH, OR, SD
Mental Retardation Diagnostic Developmental Disability and Related Criteria Conditions Pervasive Developmental Disability	MA, NV, TX, VT, UT, WY	AK, GA, IN, KS, LA, MI, MO, MS, ND, OH, OR,
Spina Bifida	UT, WY	DC, FL, GA, IN, KS, LA, MI, MO, MS, ND, NJ, NM, NY, OH, OR, WV
Fetal Alcohol Syndrome	NV, TX, UT, WY	AK, GA, IN, KS, LA, ND, NY, OH, OR, SD
TBI before18	CT, WY	DE, IN, MO, MS, ND, NY, OR,
TBI before 22	NV, TX, UT	AK, GA, KS, LA, MO, ND, NJ, NY, OH, OR, SD, WV
At Risk before 6	NV, TN, VA	AZ, LA, ND, OH, OR
Other	MA, PA, VA	AR, CA, CO, DC, DE, ID, IN, LA, MI, MO, MT, NC, NH, NJ, NM, NY, WA

[6] and Moseley, Charles and Zaharia, Ric, *"State Strategies for Determining Eligibility and Level of Care for ICF/MR and Waiver Program Participants"*, Rutgers, July 2008, p.6.

Some states have a limited, specific list of diagnoses that initially qualifies an individual.[7] Other diagnoses, while possibly adding documentary weight to the individual's eligibility, are not sufficient to establish related conditions eligibility. For diagnoses not specifically noted as meeting related conditions eligibility is established using the functional assessment and other documentation (age of onset of the person's functional limitations for example.) When these diagnoses present, the state may wish to include an operational expectation of state level review to ensure consistency across the state.



Like in North Dakota, specific conditions are often added due to legislation. In general, states have found it difficult to make any type of exhaustive list of diagnoses. States do rely on some specific diagnoses and a determination of developmental disability or related condition through a combination of assessments and professional judgement.

States do struggle with eligibility determination for individuals who may have what appear to be related conditions—but the individual does not require the type of habilitative services typically provided to individuals with I/DD. North Dakota indicated difficulties in distinguishing between individuals who are DD but not similar to someone with ID? For example, should individuals with minimal cognitive deficits, learning disabilities, physical disabilities, kids with MS/MD, CP, or other conditions that may have DD but no cognitive impairment be eligible under related conditions?

[7] As long as age of onset is met and the limitations are likely life long

Recommendation: There are some states that indicate individuals with related conditions but no intellectual disability and the capacity to oversee and manage their own services are not included in their eligibility for HCBS waivers serving individuals with ID/DD. This exclusion may include for example, individuals with cerebral palsy or epilepsy and no cognitive impairments who can manage their own planning. These individuals would be served on programs intended for individuals with physical disabilities as their needs may more closely align with the supports and services afforded individuals with physical disabilities. Wisconsin has developed criteria used to ascertain if someone is eligible for a DD waiver or more appropriately served on another program that may be of interest: https://www.dhs.wisconsin.gov/publications/p00944.pdf (NAT)

A number of questions arose regarding individuals with cognitive limitations who do not meet eligibility as the limitations do not constitute an intellectual disability based in I.Q. scores. Because limitations or deficits are typically related to cognitive limitations and DD services are designed to support people to become more independent and who have cognitive limitations, the questions arose:

- Is there an IQ range where cognitive limitations can be considered "appropriate" when a person does not have a diagnosis of ID but still fits the definition of cognitively impaired? Should all conditions just go through the criteria to determine one way or another?

Individuals with cognitive impairments but not an "official' intellectual disability could still meet eligibility under related conditions if they meet the functional impairment, age of onset and need for DD services criteria.

A specific question was posed regarding individuals with Autism Spectrum Disorder (ASD):

- Often people are referred that have ASD and an average IQ. They may have 3 areas of substantial limitations for meet the criteria for DD, however, when the questions is asked if it is similar to a person with ID-how should that be determined when the person does not have low IQ but has cognitive impairments related to ASD? What if the person has support needs for prompting but understands how to complete when prompted?

In terms of individuals with ASD, at issue is does the person meet the related conditions functional impairments criterion and does the individual have a need for and can benefit from the DD services? Individuals with ID also may be able to follow prompting, so this specific question has applicability to more than individuals with ASD.

Recommendation: It makes sense that unless the individual clearly meets the ID criterion (and needs services—not all individuals with ID need supports—but that's a person-centered planning issue), the process for assessment and determination of a related condition should be invoked for individual with cognitive impairment other than ID.

Issue: Eligibility for dual diagnosed individuals

Staff indicate that eligibility determinations are extremely challenging when a person has a Mental Health diagnosis and ID. It is difficult to ascertain if limitations are related to ID/cognitive deficits vs. mental illness, drug abuse/additions, etc. This is a problem faced across the nation and is particularly difficult dues to our "silo-ed" systems. A few states have done some very good work on identifying and serving this population. Ohio and New Mexico stand out for their cross system approaches. We also suggest that the NADD a national association dedicated to serving individuals with I/DD and mental health needs has excellent training and support information on this population found at: http://thenadd.org/.

Issue: Children's eligibility criteria and determination process

According to experts in assessment of children, assessing children requires the following key components:

- Clinical judgment plays a critical role throughout
- Use well normed and standardized assessment instruments
- Complement standardized assessment tools with a review of existing information from other sources plus other conversations/interviews with others
- Include information from multiple sources and multiple respondents[8]

This same advice is reinforced in AAIDD's "User Guide " which notes:

- Use standardized assessment instruments
- Select appropriate measures of adaptive behavior (normed on typical population – with appropriate same-age peers);
- Use multiple informants/sources/contexts;
- Assess in environments typical of individuals age and culture;
- Assess typical/actual functioning and NOT capacity or maximum ability;
- Many social adaptive skills not assessed on current measure of adaptive behavior (e.g., gullibility, naiveté)
- Adaptive behavior and problem behavior are separate constructs –and are not necessarily related[9]

North Dakota's internal guidance found in the Eligibility for DDPM document closely follows this advice. The combination of standardized assessment , interviews, observation and clinical judgement really is standard practice for the assessment of children. Although North Dakota certainly can lay out process and criteria for eligibility, the rules cannot fully substitute for professional judgement.

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[8] Tassé, M. J. (2016) – Maryland DD Coalition sponsored presentation titled: "*Diagnosing and Evaluating Children with Developmental Disabilities."* Baltimore, MD

[9] Schalock, R. L., Luckasson, R. A., Bradley, V., Buntinx, W. H. E., Lachapelle, Y., Shogren, K. A., Snell, M. E., Tassé, M. J.,Thompson, J. R., Verdugo, M. A., & Wehmeyer, M. L. (2012). Intellectual disability: Definition, classification, and system of supports (11e) - User's Guide. Washington, DC: American Association on Intellectual and Developmental Disabilities

- A specific question arose about how to look at adaptive skill limitations for younger children. The DDPM information indicates that, "Any assessment can be used that will yield a percentage delay."

Recommendation: You may wish to specify the assessments to assure they are valid and reliable tools that are properly normed on the population you intend to serve. Common adaptive assessments used in the ID/DD field include:[10]

Vineland Adaptive Behavior Scales – 2nd Edition (Ages: 0 – 90 years old)
Adaptive Behavior Assessment System – 3rd Edition (Ages: 0 – 89 years old)
Scales of Independent Behavior – Revised (Ages: 3 months – 80+ years old)
Adaptive Behavior Diagnostic Scale (Ages: 2 – 21 years old)
DAYC-2: Developmental Assessment of Young Children–Second Edition (Ages 0-11)

There are other age specific tools developed by individual states that also could be used to determine eligibility initially and at intervals to make a redetermination. The Minnesota Child Development Inventory and Wisconsin's Children's Long Term Support Functional screen (https://www.dhs.wisconsin.gov/functionalscreen/cltsfs/mod1.htm) are two more options.

A comprehensive list of adaptive assessment tools for children can be found at: http://www.fpnotebook.com/legacy/Peds/Neuro/MnstChldDvlpmntlInvntry.htm

Concern as expressed about the how to determine in children, if the limitations will be lifelong. The related conditions criterion is,"…it is likely to continue indefinitely." North Dakota's guidance indicates, "The term "indefinite" is not intended to automatically exclude all disabilities, which cannot be shown to be of a chronic nature. Therefore, determination of this threshold must involve a sequence of thinking resulting in a combined conclusion. If the body system that is impaired is one which is known not to regain capacity once damaged, or the condition causing the impairment is one which is known to be chronic with little expectation of remediation, or in the professional judgment the person is likely to remain impaired for the foreseeable future; and the disability is likely to ensure even if educational interventions, environmental modifications or similar efforts are made to increase the person's ability to function, the threshold is met for the disability is likely to continue."

Recommendation: In many states, the criteria for the Part C 0-3 program make sense as an eligibility platform for children 3. Part C under 'reframes' the lifelong criterion and states, "….(i) Has a high probability of resulting in developmental delay;…"[11]. North Dakota has an excellent 0-3 guide that might be useful.[12] For older children, measuring functioning against developmental stages at perhaps more frequent intervals than annually may satisfy concerns.

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[10] Tassé, M. J. (2016) – Maryland DD Coalition sponsored presentation titled: "*Diagnosing and Evaluating Children with Developmental Disabilities."* Baltimore, MD
[11] § 42 CFR 303.21 Infant or toddler with a disability.
[12] Birth to 3 Early Learning Guidelines, ND DHS: https://www.nd.gov/dhs/info/pubs/docs/cfs/2009-08-earlylearning-birth-3.pdf

It is important to note that the HCBS regulations state, "That the recipient, but for the provision of waiver services, *would* otherwise be institutionalized.."[13] This allows for a broader interpretation of meeting eligibility and could help inform all eligibility determinations.

Eligibility for the ID/DD HCBS Waiver

Level of Care (LOC) process

Eligibility for the HCBS waiver is the second component to eligibility. North Dakota developed the DDD-PI-090, a policy designed to assist DDPM's in determining if an individual meets the ICF/IID level of care to access Title XIX Medicaid services for ICF/IID community group homes and the DD Home and Community Based Waiver.

For individuals 3 and over, the case manager completes the Gollay Grid. The Gollay Grid is essentially a checklist with guiding examples of what constitutes substantial limitations in key life areas. The DDPM also completes the Progress Assessment Review (PAR) which is an evaluation to determine whether an individual meets the minimum criteria for the ICF/IID level of care. The PAR also identifies the level of supports an individual may need in residential, day services, motor skills, independent living, social, cognitive, communication, adaptive skills, behavior, medical, and legal. This is completed initially, annually, and as needs may change or individuals age 3 and over. The PAR answers are in entered into Therap (an electronic documentation system), where a formula is used to determine the PAR score, PAR level, and HCBS indicator. The HCBS indicator is either a yes, no, or professional judgment.

Recommendation: The initial eligibility assessment, Gollay Grid and PAR appear to collect much of the same information in different formats. We strongly suggest that the state, for adults, adopt one comprehensive assessment that can be used to ascertain "system" eligibility and level of care.
Many states discover in looking at eligibility data, that typically if an individual with ID/DD is "system' eligible there is a high likelihood that they meet LOC. A few states do have more "liberal" definitions of DD (such as two functional impairments) that result in some individuals not meeting LOC.

Just a note—the PAR seems to invoke rather stringent standards asking many highly detailed functional status questions that may not be necessary to establish LOC. Also the type of questions are not usually used for establishing LOC. You may want to ascertain if the PAR is necessary for LOC or other purposes.

Recommendation: The state could analyze eligibility determination data to ascertain if a significant number of "system' eligible individuals do not meet LOC. If so, this would suggest that screening for LOC remain separate from system eligibility screening. Conversely if there is a high correspondence between LOC and system eligibility, the state may opt for one eligibility assessment tool/process. Individuals found ineligible could still be reviewed using professional judgment.

[13] § 42 CFR 441.302(c)(1)(ii)

LOC Criteria: Active treatment

The instructions for DDPM's in assessing LOC note, 'Would the person benefit from active treatment if residing in an institution (ICF/MR)?" While institutional eligibility is of course deeply linked to HCBS waiver eligibility, active treatment is not a HCBS waiver requirement. CMS issued a letter about the ICF-IID LOC that notes, "The applicability of active treatment, therefore, is limited to the institutional setting. Federal Law requires that individuals served under the waiver would be eligible, in the absence of the waiver, to receive active treatment in an institution (in this case, an ICF/MR)." The letter also notes, "As the balance of care has subsequently shifted from institutional to home and community-based care, the more severely disabled in have tended to remain in institutions. Moreover, because community-based services tend to be more accessible to higher functioning individuals, these consumers have been more inclined to choose community-based care services over institutional care. As a result, ***the profile of individuals receiving home and community-based care may differ from those served in institutions. However, it would be a mistake to conclude that certain high functioning individuals would not require ICF/MR services*** merely because their functional abilities exceed the levels ordinarily seen in 1CFs/ nowadays."[14]

Recommendation: ND may wish to amend the LOC and active treatment guidance to reflect the CMS letter. Additionally it is worth remembering that the HCBS waiver LOC for ICF/IID is based on a 1981 standard. At that time individuals were provided institutional services (as these were typically what was available, who now, because of the HCBS waiver would not be institutionalized.

Eligibility for E and D waiver

While there were not a significant number of concerns raised about the E and D waiver other than the concern about related conditions and assessing for I/DD or E and D waiver eligibility, addressed earlier in the report, a number of stakeholders did raise a concern that the level of care screening tool and process may raise specific issues for individuals with brain injury. The state has an active workgroup currently meeting to discuss the applicable level of care criteria and its implications for individuals with TBI.

Recommendation: Review tools and process to ensure equal application across all target groups served or potentially served in the waiver. Review historical documents and processes to ascertain whether certain elements could be reintroduced to ameliorate this concern.

We did note that compared to states with similar population size, North Dakota serves considerably fewer individuals than any other state. [15] We do note that North Dakota has two

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[14] MEDICAID LETTER NUMBER: 97-10, SUBJECT: Guidelines Regarding What Constitutes an ICF/MR Level of Care Under a Home and Community-Based Services Waiver Region III, Health Care Financing Administration, DEPARTMENT OF HEALTH and HUMAN SERVICES, March 6, 1997

[15] Kaiser Health Facts, Medicaid Home and Community-Based Services Programs: 2013 Data Update, p. 37

significant state-funded programs (SPED and EX_SPED) that serve a many individuals across the state. We note that these programs may be providing important preventive strategies for individuals who are above assets, allowing them to receive needed supports without a requisite spenddown to Medicaid eligibility.

Additionally, we noted that eligibility requires that individuals must be, "…Capable of directing his/her own care,…" While this may be appropriate for self-directed services, the state has clarified that individuals may have the support of a guardian or representative and be enrolled in the waiver. Barring this ability to receive support in directing care, this requirement may have an unintended effect of narrowing waiver eligibility. We recommend that the state clarify this and incorporate this information into educational materials regarding available services and supports.

In addition, consider building upon the work of the focus group convened pursuant to SB 1378 regarding the medically fragile waiver and the work of the TBI and Medicaid services workgoup, which sought to fill gaps in services but also provided a strong stakeholder effort regarding level of need determinations and eligibility criteria for these two populations.

DD Assessment Tools

California Client Development Evaluation Report: http://www.dds.ca.gov/CDER/Index.cfm
Developmental Disabilities Profile:
https://opwdd.ny.gov/sites/default/files/documents/DDP2_User_Guide_0.pdf
InterRAI: http://interrai.org/intellectual-disability.html
Supports Intensity Scale (SIS): http://aaidd.org/sis#.WTmc_oWcGHs
Washington: DDA Assessment: https://www.dshs.wa.gov/dda/consumers-and-families/dda-assessment
Wisconsin Functional Screen: https://www.dhs.wisconsin.gov/functionalscreen/index.htm

Acronym Key:

ASD	Autism Spectrum Disorder
DD	Developmental Disability
DDPM	Developmental Disabilities Program Management/Manager
HCBS	Home and Community-Based Services
ICF/IID	Intermediate Care Facility for Individuals with Intellectual Disabilities
ID	Intellectual Disability
IQ	Intellectual Quotient
LOC	Level of Care

Person-centered Planning Practices

Person-centered Planning Practices

Federal Code **442.301 (C) (2)** ***The Person-Centered Service Plan*** clarifies the expectations of person centered planning requirements for people using HCBS. The person-centered service plan must reflect the services and supports that are important for the individual to meet the needs identified through an assessment of functional need, as well as what is important to the individual with regard to preferences for the delivery of such services and supports. Commensurate with the level of need of the individual, and the scope of services and supports available under the State's 1915(c) HCBS waiver.

Person Centered Planning is an ongoing process and not a single event. Person centered plan development should be at the forefront of every conversation with the person, their family, and support workers from the earliest stages of engagement with the person in the service delivery system. From intake through discovery and information gathering, including monitoring of service delivery, person centered practices should be embedded within the system. The foundation of questions need to move from functional limitations, barriers and challenges, and inability, to capabilities, strengths, opportunities and interests. Building upon interests, talents and skills is a solid foundation on which to build community engagements, employment opportunities and develop expanded social relationships. The core foundation of person-centered practice should assume everyone has the desire and intention to either learn new skills or habits, acquire, maintain or expand the ability to do things for one's self and to engage in the community to the same degree as those who do not receive Medicaid services.

The order in which questions are asked matters in person centered planning. If people are to make informed decisions, the planning process must start with how each person wants to live before asking where they want to live and who supports them. It is not only important what we discover about people when developing plans, but how information is relayed about the person. People with disabilities and older adults are often introduced by a document – a person centered plan, a person centered care plan, etc. Nearly all of these documents begin with the disability and level of function, what the person can and cannot do. When this information is presented first, the perception of a person who cannot make choices and needs someone else to do that for them is reinforced.
The CMS final rule creates pressure for positive change. One way to think about the requirements is that each person receiving HCBS will be supported, through a process, to make an informed decision about:

- Who (organization) supports them
- Where they live
- Who they live with
- How they spend their time, including opportunities for employment
- How they use their resources

- How supports and services are provided for them

The resulting person centered plan should:

- Describe the balance between "important to" and "important for"
- Assist in managing risk to support informed choice and provide incentive for the dignity of risk
- Have two key components: person-centered description; and actions with outcomes
- Address the manner in which privacy health, wellness and safety are to be achieved for the person, according to their preferences and needs.

Supports for Individuals with I/DD

CMS specifies that service planning for people in the 1915 c HCBS Waivers must be developed through a person centered planning process. Further, CMS states that the planning process should addresses health and long term services and supports needs in a manner that reflects the individual preferences and goals. In North Dakota for people with I/DD, person centered planning is accomplished through the development of the Overall Service Plan, or OSP. The OSP is composed of two sections, the State Individual Service Plan (ISP) and the Person Centered Service Plan (PCSP). The OSP describes the person's individual goals/outcomes as well as the supports and services, both HCBS and other services, needed in order to ensure the person accomplishes these goals/outcomes. As in most states the case manager responsible for the development of the plan meets with the person receiving services and their families and/or legal representative if applicable to discuss what the person desires to accomplish, obtain, maintain, learn, discover, etc. in order inform the OSP and planning process. ND also uses a variety of assessments that provide additional information for the development of the annual OSP.

Assessments

North Dakota uses a number of assessments during the planning process to determine Level of Care (LOC) and to inform the OSP. These assessments include:

- The Progress Assessment Review (PAR)
- Risk Assessment (RMAP)
- Individual Protective Oversight Plan (IPOP)
- Individual Protective Oversight Plan - Residential Version
- The Self-Assessment

All assessments, with the exception of the Self-Assessment, require the use of a standardized template. The standardized assessment tools extensively review the support needs, functional deficits and limitations of the person, and health and safety issues. The majority of the information gleaned from the assessments does not lend itself easily to the development of a truly person centered plan because the information is not gathered in the context of personal preferences and goals or things important to the person. In fact, some of the assessment items are counter-intuitive in the development of the OSP as a person centered plan. Most items from the PAR assessment do not take into account the foundational principles of person centered

planning such as important to the person or important for the person when scoring. For example, an item rates the person's functional ability for "inappropriate undressing". In this PAR example, inappropriate undressing is defined as attempts to or taking off clothing items at inappropriate times or repeatedly, example taking off coat when outside in the cold. This item assumes that everyone has the same rituals and routines regarding dressing and there is no room for personal preference allowed. Furthermore, the person may be most comfortable changing clothing repeatedly in the privacy of their own home or going without a coat in cold weather because a coat may feel confining to them. It would not make sense to score this item the same for all people when taking into account individual preference. If this item is not something important to or for the person, there is no need to address at any level. The Risk Assessment and the Individual Plan of Protective Oversight (residential version) contain similar items that are not person centered in nature and would have very little impact on the supports and services each person receives.

The Self-Assessment is the North Dakota assessment tool for people with IDD intended to capture true person centered information such as what is important to the person, individual strengths, preferences and needs. The requirements for the Self-Assessment are very general in nature and loosely defined. Specific training for staff responsible for completing this assessment is not offered/required. Lack of concrete guidelines and requirements for this assessment is problematic. Discussions with state staff reveal that results of the assessment vary widely among providers in terms of content used to inform plan development.

Recommendations

North Dakota would benefit from a review of the required planning assessment tools in order to identify opportunities to streamline the process and the lessen number of tools required to be updated on an annual basis. It would be a beneficial exercise to evaluate the usefulness of all information gathered by the many assessments in regards to the development of a true person centered plan. The ND DD Overall Service Plan Instructions document states, "*the assessment process should help the person and the teams identify the person's overall goals*". Unless an assessment item assists the person in identifying their overall person goals and objectives, is the assessment item serving its intended purpose?

The Self-Assessment is the key person centered assessment document in ND used to inform development of true person centered plans. However, without structure, the assessment could be less effective than desired. ND should consider requiring the use of some of the internationally recognized person centered planning tools and processes to ensure consistent application of the assessment. Some states have requirements around the use of specific person centered thinking tools and person centered planning processes such as Essential Life Style Planning (ELP), PATH, MAPs, WRAP, etc., to be used during the planning process to ensure a person centered plan that supports an individual's personal outcomes/goals as well as strengths and support needs.

ND currently utilizes CQL's Personal Outcome Measures (POM) tool for people using IDD HCBS. When applied correctly, the POM tool offers a goldmine of information for people regarding what is important to and for them in order to have a quality life. ND should examine their use of this tool to determine how to use this information to inform person centered planning.

The Overall Service Plan (OSP)

North Dakota uses a prescribed template housed in a web-based platform for their OSP for people using IDD services. Various entities including state case managers and service provider program coordinators are responsible for entering information into the template based on the results of the assessments, conversations with the person and family, and discussion held during the annual in person planning meeting. There is a very detailed instruction manual called "Overall Service Plan Instructions (12/19/16)". The manual describes the mechanics of service planning including how to navigate the template, who is responsible for what pieces of the OSP, determining due dates for planning activities, explanations of various text fields, etc… The manual does contain some high level information regarding expectations of the OSP as it relates to person centered planning. However, more formalized training regarding person centered thinking and planning is needed in order to develop more quality OSPs that are person centered. In addition, the fields required in the template focus almost entirely on issues of health, safety and results of functional assessments. The template itself may be a barrier to developing a good person centered plan due to lack of opportunity to document the person's preferences, desires, likes, and support needs based in things that are important to that person. It is also difficult to determine how the waiver services authorized in the plan are used to support the person in accomplishing their personal goals and outcomes.

Recommendations

North Dakota DD agency should examine their current OSP template to look for opportunities to streamline information around health and welfare based on the person's individual needs and preferences so that individualized information regarding service and supports needed for each person to accomplish personal goals can be included in the plan to ensure true person centered planning.

North Dakota should consider investing in some type of person centered planning training for all the people responsible for the development of the OSP. There are many person centered thinking and planning training modules, curriculums, website resources available for consideration. Some of the examples include:

- Person Centered Thinking www.learningcommunity.us/person.html and http://helensandersonassociates.co.uk/person-centred-practice/
- PATHS and MAPS - http://www.inclusion.com/bkpcpmapsandpath.html
- Essential Lifestyle Planning - http://www.learningcommunity.us/elp3.html
- CQL's Personal Outcome Measures - https://c-q-l.org/the-cql-difference/personal-outcome-measures

Supports for People Who Are Aging

Similar to the CMS requirements for people who have IDD, service planning for people who are aging must be completed by using a person centered planning process. North Dakota's person centered plan for people using HCBS in the aging and disabled program is called the Person Centered Plan of Care. The Person Centered Plan of Care consists of ten (10) sections including a listing of HCBS services and providers, functional limitation scores, risk assessment and other administrative information. The Risk Assessment section of the plan includes a listing of the person's strengths and needs in various areas including employment, decision making, falls, mental health, and family among others. In addition, each area in the

reviewed in Risk Assessment includes an opportunity to establish goals in that area. The purpose of these goals is to mitigate the acknowledged risk in the person's daily life.

Assessment

An annual assessment is completed for each person receiving HCBS services in the ND Aged and Disabled waiver program as part of the planning process. The assessment, titled HCBS Assessment, includes demographic information; functional needs review and review of health and safety issues. As with most assessments, the information gathered during the assessment process is used to produce the Person Centered Plan of Care. The HCBS Assessment does not include tools or indicators to assist in the determination of what is important to the person or strengths, preferences and interests. Currently there is no identified discovery process used that would assist in gathering true person centered information. The assessment is lengthy, numbering fifteen pages (15).

Recommendations

North Dakota would benefit from a review of the HCBS Assessment in order to identify opportunities to streamline the process focus the discovery process on information needed to develop a person-centered plan that identifies each person's goals and outcomes and the supports and services needed to attain those goals.
ND should consider requiring the use of some of the internationally recognized person centered planning tools and processes to ensure consistent application of a person centered assessment. ND could either adapt the HCBS Assessment to include both eligibility determination items and add assessment information geared toward determining what is important to a person in specific life domains. ND could also consider revising the Person Centered Plan of Care template to include person centered planning tools or content that would capture the same information that a stand alone person centered assessment would contain.
Some states have requirements around the use of specific person centered thinking tools and person centered planning processes such as Essential Life Style Planning (ELP), PATH, MAPs, WRAP, etc., to be used during the planning process to ensure a person centered plan that supports an individual's personal outcomes/goals as well as strengths and support needs.

Person Centered Plan of Care

According to the 1915 (c) Medicaid Waiver ND P&P manual "Care Planning is a process that begins with assessing the client's needs. It includes the completion of the HCBS comprehensive assessment after which the case manager and client look at the needs and situations described in the comprehensive assessment and any other problems identified and work together to develop a plan for the client's care". The ND Person Centered Plan of Care is developed using a prescribed template that begins by describing the services needed, ADL (Activities of Daily Living) and IADL (Instrumental Activities of Daily Living) scores, and concludes with five (5) pages of risk assessment. While Section X. Waiver Risk Assessment does describe strengths, needs and goals

for various areas, this section is utilized as risk mitigation and does not consider the preferences, likes and personal goals identified by the individual being assessed. While risk identification and mitigation are very important components of a person centered plan, they should also be discussed in the context of personal goals, strengths, interests and what is important to the person. The development of goals based on what/how/why as included in the Person Centered Plan of care template, is a nice start to organizing the document to address true individualized goals.

Recommendation

North Dakota DD agency should examine their current Person Centered Plan of Care template to look for are opportunities to streamline information around health and welfare based on the person's individual needs and preferences. Consider starting with the individual goals and outcomes in each plan and building remainder of the Person Centered Plan of Care content around those.
North Dakota should consider investing in some type of person centered planning training for all the people responsible for the development of the PC Plan of Care. There are many person centered thinking and planning training modules, curriculums, website resources available for consideration. Some of the examples include:

- Person Centered Thinking www.learningcommunity.us/person.html and http://helensandersonassociates.co.uk/person-centred-practice/
- PATHS and MAPS - http://www.inclusion.com/bkpcpmapsandpath.html
- Essential Lifestyle Planning - http://www.learningcommunity.us/elp3.html
- CQL's Personal Outcome Measures - https://c-q-l.org/the-cql-difference/personal-outcome-measures

Supporting Families

To be person centered, it is vital that planning is done within the context of families. Supporting people with disabilities to live and fully participate in their communities throughout their lives has emerged as a fundamental right and consideration in disability policy and practices. Because of the role that families continue to play in the lives of their family members, future policies and practices must reflect the family as part of the system of support.
Disability service systems, through both state and federal programs, furnish a wide array of services and supports to individuals with I/DD. These services and supports provide opportunities for individuals with I/DD to maximize their full potential and participate in their families and community. Therefore, state disability system are driving forward innovative services, such as family specific strategies and family- and person- driven services.

The Supporting Families Community of Practice is a multi-state learning community focused on supporting people with disabilities to have good lives and strengthening their families in order to provide supports across the lifespan of the person. Many tools and resources valuable to state systems to consider when developing person centered planning processes are being developed

and tested as part of this community of practice. More information can be found at www.supportstofamilies.org

A Word about Language

Many states have undertaken the task of reviewing the language and professional jargonused in their policies, procedures, required templates and forms to look for opportunities to remove language that may demonstrate an institutional bias, antiquated terms or terms that can diminish a person's perceived value or contribution to the community. Words such as client, mental retardation, functional limitations, etc. are antiquated have long been regarded by self-advocates as less than respectful. It is hard to overstate the importance of language. Language to avoid in conversation, P&Ps, documents, etc. includes

- Language that makes people different from us
- Language that makes people the object of a process rather than a participant
- Language that diminishes the person or their contribution, or references people as objects

As North Dakota continues on the path to being a person centered system, it is vital to consider the language used in order to convey the system values. Below are links to several resources for using person-centered language.

http://www.r-word.org/r-word-effects-of-the-word.aspx
http://ncdj.org/2015/09/terms-to-avoid-when-writing-about-disability/
https://www.thearc.org/who-we-are/media-center/people-first-language

Services: Availability and Access

In the section below, we will provide a brief overview of the types of services and supports available within Medicaid in North Dakota, in addition to two generous state-only funded programs. In Medicaid, it is important to consider the entirety of the benefits available to an individual (not just within a waiver) as you assess the coverage for any given group. Consequently, this section will first provide an overview of the services and supports available to *all* Medicaid-eligible individuals then will provide information on the service coverage by specific waiver program. All individuals served in the HCBS waiver program must meet the applicable levels of care for the waiver.

NORTH DAKOTA MEDICAID STATE PLAN BENEFITS

State plan benefits are available to any Medicaid-eligible individual who has a medical necessity (need) for the service. The section below provide an overview of the mandatory and optional benefits covered in North Dakota[16], as well as those optional benefits that North Dakota has elected to cover. Service availability for children is different than for adults, and the children's coverage description is included below in the section entitled **Early Periodic Screening, Diagnostic and Treatment (EPSDT) Benefit.**

Hospital

Inpatient: Covers room and board, regular nursing services, supplies and equipment, operating and delivery room, X-rays, lab and therapy.

Outpatient: Covers emergency room services and supplies, lab, X-ray, therapies, drugs and biologicals, and outpatient surgery.

Nursing Facility

Covers room and board, nursing care, therapies, general medical supplies, wheelchairs, and durable medical equipment.

Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/ID)

Covers comprehensive and individualized health care and rehabilitation services to individuals to promote their functional status and independence.

Personal Care Services

Clinics, Rural Health Clinics

Covers outpatient medical services and supplies furnished under the direction of a doctor.

Hospice

Provides health care and support services to terminally ill individuals and their families.

Physicians

Covers medical and surgical services performed by a doctor; supplies and drugs given at the doctor's office; and X-rays and laboratory tests needed for diagnosis and treatment.

Prescription Drugs

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[16] Adapted from list available at: http://www.nd.gov/dhs/services/medicalserv/medicaid/covered.html. July 1, 2017. Note: additional service limitations may apply. Note: This list was augmented to include personal care and ICF/ID as both are covered State Plan benefits in ND.

Covers a wide range of, but not all, prescription drugs, insulin, family planning prescriptions, supplies, and devices. Requires a prescription from a doctor. Pharmacists can tell you if a particular drug is covered by Medicaid.

Chiropractor

Covers X-rays and manual manipulation of the spine for certain diagnosis.

Health Tracks (EPDST) – See section below

Covers screening and diagnostic services to determine physical and mental status, and treatment to correct or eliminate defects or chronic conditions and help prevent health problems from occurring for children under 21. Also covers medically necessary orthodontia and vaccinations.

Home Health

Covers nursing care, therapy and medical supplies when provided in a recipient's home. Care must be ordered by a physician.

NOTE: CMS has issued a new regulation that stipulates that home health cannot be limited to in-home services and also makes changes to the equipment and supplies requirements. This rule becomes effective Jan 2018 and may alter what is available in North Dakota under this benefit.

Durable Medical Equipment and Supplies

Covers medical supplies such as oxygen and catheters and reusable equipment that is primarily medical in nature. Items must be medically necessary and do not include exercise equipment, personal comfort or environmental control equipment.

Dental

Covers exams, X-rays, cleaning, fillings, surgery, extractions, crowns, root canals, dentures (partial and full) and anesthesia.

Family Planning

Covers diagnosis and treatment, drugs, supplies, devices, procedures and counseling for persons of child bearing age.

Sterilization

Covers sterilization procedures if: (1) The recipient is at least 21 years old; (2) The recipient is legally competent; (3) The recipient signs an informed consent form; and (4) At least 30 days but not more than 180 days have passed between the signing of the consent form and the sterilization.

Podiatry

Covers office visits, supplies, X-rays, and surgery procedures.

Mental Health

Covers psychiatric and psychological evaluations, inpatient services in a psychiatric unit of a hospital, individual-group-family psychotherapy, partial hospitalization services, and inpatient psychiatric and residential treatment centers services for individuals under 21 for the care and treatment of mental illness or disorders.

Ambulance

Covers ground and air ambulance trips, attendant, oxygen, and mileage when medically necessary to transport a recipient to the closest health care facility meeting his needs. House Bill 1282 permits ambulance personnel to refuse transport to an individual where medical necessity cannot be demonstrated and recommend an alternative course of action for the individual. If the ambulance was not medically necessary, Medicaid will not pay for the service.

Transportation

Covers non-emergency transportation services to and from the recipient's home to the closest medical provider capable of providing a medically necessary examination or treatment.

Vision

Covers exam, glasses, frames and some hard contact lenses for the correction of certain conditions. Replacement eyeglasses may only be provided after a minimum of 12 months for children under 21 or 24 months for adults if a lens change is medically necessary. An exception to the replacement limitation may be made if new eyeglasses are required for a significant change in correction and the eyeglasses are prior approved. Lost or broken glasses for individuals over 21 will not be replaced within the first two years.

Therapies

Covers physical and occupational therapy and speech and language pathology.

Out-of-State Services

Medically necessary covered services may be provided outside of North Dakota if the services are not available within North Dakota and have been prior approved by the department or if the services are provided in an emergency situation.

Under Medicaid, State Plan benefits should be utilized before all other service coverage areas if available. The processes used to ascertain the availability of services directly impacts the person-centered planning processes and authorization practices for the 1915(c) HCBS programs, as these two authorities work in tandem to provide the whole (or the vast majority) of LTSS and related services available to individuals.

EARLY PERIODIC SCREENING, DIAGNOSTIC AND TREATMENT (EPSDT) BENEFIT

The Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit provides comprehensive and preventive health care services for children under age 21 who are enrolled in Medicaid. EPSDT is key to ensuring that children and adolescents receive appropriate preventive, dental, mental health, and developmental, and specialty services.

- **Early:** Assessing and identifying problems early
- **Periodic:** Checking children's health at periodic, age-appropriate intervals
- **Screening:** Providing physical, mental, developmental, dental, hearing, vision, and other screening tests to detect potential problems
- **Diagnostic:** Performing diagnostic tests to follow up when a risk is identified, and
- **Treatment:** Control, correct or reduce health problems found.

States are required to provide comprehensive services and furnish all Medicaid coverable, appropriate, and medically necessary services needed to correct and ameliorate health conditions, based on certain federal guideline. This means that, in addition to the services that North Dakota has elected to cover under the state plan, the state must provide *any* service that could be covered under the state plan to a Medicaid-eligible child who has a need for the service.

CMS has issued guidance during the past two years to highlight state obligations under this statutory requirement (See Attachment 1). This has required states to undertake a comprehensive review of the manner in which they are making services available to children and to make changes to ensure that any potentially coverable service is available to all children. Some states had historically utilized 1915(c) waivers to cover services over and above that which was covered under the state plan. For children, the state plan benefits have no limits beyond medical necessity, so the increased CMS enforcement has resulted in some states needing to recalibrate their service structures to make sure that the benefits were indeed available to all children. One common example of this required states to move certain services from an autism waiver to their state plan EPSDT benefit. These services may have included applied behavioral analysis (ABA) or training for families on clinical behavioral interventions. This has also arisen in other waivers, where non-emergency medical transportation may have been provided. In both examples, states are in the process now of developing and implementing new state plan processes to effectively address the needs in a timely manner.

North Dakota's EPSDT Program is called Health Tracks.

HOME AND COMMUNITY BASED SERVICES

North Dakota currently operates six (6) 1915(c) waiver programs. These programs, designed to meet the needs of specific target groups within the state, vary by size (numbers of individuals served), service array, eligibility criteria and operational practices. Table 1.0 below illustrates the waivers, their identified target groups and the number of individuals the state anticipates serving in the current waiver year. Table 1.1 below provides an at-a-glance review of the services available in each waiver. In addition to these Medicaid programs, North Dakota offers two significant state-funded programs, Service Payments for Aged and Disabled (SPED) and Expanded SPED, that also provide home and community based supports to individuals meeting specific eligibility criteria.

North Dakota 1915(c) HCBS Waiver Programs			
Medicaid Waiver or State-Funded Program	**Target Group**	**Number of Individuals (Maximum Capacity)[17]**	**Date of Next Renewal**
ND Medicaid Waiver HCBS (0273.R04.00	Individuals who are aged 65 – no max age, disabled-physical ages 18-64, and disabled-other ages 18-64 yrs.	496	2022
Children's Hospice (0834.R01.00)	Medically fragile individuals ages 0 – 24 Child will have a letter from their primary physician stating they have a life limiting diagnosis that could possibly be end of life, within one year or less.	30	2018

[17] As indicated in approved waiver for current waiver year. Source: Centers for Medicare & Medicaid Services 06/30/2017

North Dakota 1915(c) HCBS Waiver Programs			
Medicaid Waiver or State-Funded Program	**Target Group**	**Number of Individuals (Maximum Capacity)[17]**	**Date of Next Renewal**
ND Autism Spectrum Disorder (0842.R01.00)	Children with autism 0-7.	47	2018
ND Traditional ID DD HCBS (0037.R07.00)	Individual w/ID DD ages 0 - no max age The state additionally limits the waiver to individuals with intellectual disabilities or individuals with related conditions and cognitive impairment.	5470	2019
ND Medicaid Waiver for Medically Fragile Children (0568.R01.00)	Medically fragile Age 3-17 Family will also need to agree to self-directing waiver services for the child.	25	2021
ND Technology Dependent Medicaid Waiver (1266.R00.00)	Age 18 – no max Individuals must be ventilator dependent for a minimum of 20 hours per day; medically stable, as documented by their primary care physician at a minimum on an annual basis, have identified an informal caregiver support system for contingency planning with the assistance of the case manager, be competent, as documented by the primary care physician at a minimum on an annual basis, to actively participate in the development and monitoring of the plan of care.	3	2021
Service Payments for Elderly and Disabled (SPED) - State funded only	Individuals who are older or physically disabled and who have difficulty completing tasks that enable them to live independently at home; Assets less than $50,000 https://www.nd.gov/dhs/services/adultsaging/homecare1.html	1231served in FY 2015	
Ex-SPED	Is at least 65 years of age, OR is at least 18 years of age and disabled or blind based on Social Security criteria; Is not severely impaired in ANY of the three activities of daily living (ADLs): Toileting, Transferring to or from a bed, chair or toilet, or Eating as determined by completion of an comprehensive assessment. Is impaired in at least three (3) of the following four (4) instrumental activities of daily living (IADLs): Meal Preparation, Housework, Laundry, or taking medicine based on completion of a comprehensive assessment. The impairments must have lasted or are expected to last, more than three (3) months. Medicaid eligible	163 served in FY 2015	

TABLE 1.0

North Dakota's 1915(c) Home and Community-Based Waiver and State Funded Program Service Array								
	ND Medicaid Waiver HCBS (0273.R04.00)	Children's Hospice (0834.R01.00)	ND Autism Spectrum Disorder (0842.R01.00)	ND Traditional ID DD HCBS (0037.R07.00)	ND Medicaid Waiver for Medically Fragile Children (0568.R01.00)	ND Technology Dependent Medicaid Waiver (1266.R00.00)	ND SPED (state funds)	ND Ex-SPED (state funds)
Adult Day Care	X							
Adult Residential Care	X							
Case Management	X	X			X (also called program mgmt)	X	X	X
Homemaker	X			X			X	X
Respite Care	X	X					X	X
Supported Employment	X							
Adult foster care	X			X			X	X
Chore	X						X	X
Emergency response	X						X	X
Environmental Modifications	X		X	X	X		X	X
Extended Personal Care	X							
Personal Care							X	
Family Personal Care	X							
Home Delivered meals	X							
Non-medical Transportation	X					X		
(Specialized) equipment and supplies	X	X	X	X	X	X		
Transitional living	X							
Supervision	X							
Hospice		X						
Skilled Nursing		X						
Bereavement Counseling		X						
Expressive Therapies		X						

North Dakota's 1915(c) Home and Community-Based Waiver and State Funded Program Service Array								
	ND Medicaid Waiver HCBS (0273.R04.00)	Children's Hospice (0834.R01.00)	ND Autism Spectrum Disorder (0842.R01.00)	ND Traditional ID DD HCBS (0037.R07.00)	ND Medicaid Waiver for Medically Fragile Children (0568.R01.00)	ND Technology Dependent Medicaid Waiver (1266.R00.00)	ND SPED (state funds)	ND Ex-SPED (state funds)
Palliative		X						
In Home Supports			X	X	X			
Intervention Coordination			X					
Adult Day Health				X				
Day Supports				X				
Extended Services				X				
Residential Habilitation				X				
Behavioral Consultation								
Family Care Option							X	X
Infant Development				X				
Parenting Support				X				
Transportation Costs for Financially Responsible Caregiver				X				
Institutional Respite					X			
Dietary Supplements					X			
Individuals and family counseling					X			
Attendant Care						X		

TABLE 1.1

As the tables above illustrate, the state has tailored service arrays to address particular needs of the target group, similar to most other states. While these benefits may have been developed with a specific target group in mind, many states often undertake a regular, periodic review of the service evolutions. These reviews may be used to determine whether other target groups could benefit from a specific service, a particular development or aspect related to the scope or duration of services, or an expansion or modification to the types of providers who may deliver services.

The utilization patterns of the services offered in a waiver can be a strong indicator of the needs of the individuals served and the demand for services. To the extent that similarly aged

individuals are served across different waivers, an analysis of this data may be helpful to determine whether similar services may be of benefit to individuals in other target groups. For example, in the waiver for individuals with I/DD, the most highly utilized services relate to infant development. To the extent that these are not duplicative of the EPSDT benefit, waivers serving other target groups (such as Autism waiver) may find it beneficial to consider similar approaches.

In addition, because waivers can include a limitation on the numbers of individual served, some states or waivers sometimes have a waiting list for services. In discussions with North Dakota staff, it was determined that most waivers do not have significant waiting lists (with the exception of the autism waiver which is slated to increase capacity in the near future). Carefully monitoring demand for services (including forecasting expected future need from pipeline programs) can be a critical tool in future planning and budgeting exercised.

One other important data source used by States to assess their resource distribution for long-term services and supports is expenditure data. Increasingly, states are tracking both the percentages of expenditures in institutional versus HCBS in efforts to assure a balanced LTSS system, but also to track the progressive growth in the service models that offer individuals the greatest opportunities for autonomy and choice.

North Dakota's expenditure data (included below) demonstrates growth in HCBS overall, with some target populations outpacing others. The table below also include recent biennium budget information for two substantial state-funded programs that are key components to the overall LTSS picture in North Dakota.

Table 1.2 Long Term Services and Support Expenditures for North Dakota [18]

Service Type	FY 2011	% Change 10-11	FY 2012	% Change 11-12	FY 2013	% Change 12-13	FY 2014	% Change 13-14
Total-Older People, People with PD	**$227,153,887**	**6.4**	**$235,244,374**	**3.6**	**$248,747,605**	**5.7**	**$270,604,668**	**8.8**
Nursing facilities	$196,293,759	4.7	$202,282,084	3.1	$211,759,719	4.7	$230,827,022	9.0
Personal care	$19,114,271	9.3	$19,866,264	3.9	$21,111,754	6.3	$22,870,849	8.3
1915(c) waivers - AD	$4,544,816	9.4	$4,706,661	3.6	$5,113,323	8.6	$5,492,513	7.4
Home health	$4,409,880	90.9	$5,197,247	17.9	$7,075,105	36.1	$7,092,308	0.2
Community first choice	n/a	n/a	$0	n/a	$0	0.0	$0	0.0
HCBS - managed care authorities - AD	$0	0.0	$0	0.0	$0	0.0	$0	0.0
PACE	$2,791,161	33.6	$3,192,118	14.4	$3,687,704	15.5	$4,321,976	17.2
Private duty nursing	$0	0.0	$0	0.0	$0	0.0	$0	0.0

[18] Wenzlow, A; Eiken, S; Sredl, K. Improving the Balance: The Evolution of Long Term Services and Supports (LTSS), FY 1981-2014. Data Tables. Downloaded from Medicaid.gov June 15, 2017

Table 1.2 Long Term Services and Support Expenditures for North Dakota [18]

Service Type	FY 2011	% Change 10-11	FY 2012	% Change 11-12	FY 2013	% Change 12-13	FY 2014	% Change 13-14
HCBS - 1915(j)	$0	0.0	$0	0.0	$0	0.0	$0	0.0
Personal care - 1915(j)	$0	0.0	$0	0.0	$0	0.0	$0	0.0
HCBS - 1915(i) - AD	$0	0.0	$0	0.0	$0	0.0	$0	0.0
SPED (State Funded)							Biennium: $15,400,000	
Ex-SPED (State Funded)							$1.600,000	
Total-People with DD	**$204,086,975**	**9.8**	**$222,700,777**	**9.1**	**$239,369,797**	**7.5**	**$265,764,343**	**11.0**
ICF/IID - public	$24,325,200	-1.8	$23,084,463	-5.1	$21,410,940	-7.2	$23,737,004	10.9
ICF/IID - private	$64,498,205	11.1	$69,061,280	7.1	$74,321,047	7.6	$73,147,143	-1.6
1915(c) waivers - DD	$115,263,570	11.8	$130,555,034	13.3	$143,637,810	10.0	$168,880,196	17.6
HCBS- managed care authorities - DD	$0	0.0	$0	0.0	$0	0.0	$0	0.0
HCBS - 1915(i) - DD	$0	0.0	$0	0.0	$0	0.0	$0	0.0
Total-People with SMI or SED	**$17,891,510**	**-11.8**	**$19,230,752**	**7.5**	**$16,515,561**	**-14.1**	**$24,512,563**	**48.4**
Mental health facilities	$8,161,323	-22.8	$8,740,228	7.1	$7,633,039	-12.7	$12,345,796	61.7
Mental health facilities-DSH	$988,477	0.0	$988,478	0.0	$741,360	-25.0	$1,235,596	66.7
Rehabilitative services	$8,741,710	0.0	$9,502,046	8.7	$8,141,162	-14.3	$10,931,171	34.3
1915(c) waivers - SMI or SED	$0	0.0	$0	0.0	$0	0.0	$0	0.0
HCBS - 1915(i) - SMI or SED	$0	0.0	$0	0.0	$0	0.0	$0	0.0
Total-Other/Multiple Populations	**$11,304,631**	**10.2**	**$11,856,278**	**4.9**	**$10,041,616**	**-15.3**	**$12,878,108**	**28.2**
Case management	$8,983,076	-3.7	$9,228,017	2.7	$8,422,682	-8.7	$10,550,609	25.3
1915(c) waivers - other	$37,002	61.1	$40,848	10.4	$29,029	-28.9	$91,347	214.7
HCBS- managed care authorities - other	$0	0.0	$0	0.0	$0	0.0	$0	0.0
Health homes	n/a	n/a	$0	n/a	$0	0.0	$0	0.0
Institutional MLTSS – unspecified	n/a	n/a	n/a	n/a	$0	n/a	$0	0.0
MFP demonstration	$2,284,553	153.0	$2,587,413	13.3	$1,589,905	-38.6	$2,236,152	40.6
Total LTSS	**$460,437,003**	**7.1**	**$489,032,181**	**6.2**	**$514,674,579**	**5.2**	**$573,759,682**	**11.5**
Total Institutional LTSS	**$294,266,964**	**4.4**	**$304,156,533**	**3.4**	**$315,866,105**	**3.8**	**$341,292,561**	**8.0**
Total HCBS	**$166,170,039**	**12.2**	**$184,875,648**	**11.3**	**$198,808,474**	**7.5**	**$232,467,121**	**16.9**
Total Medicaid (all services)	**$708,452,902**	**4.6**	**$747,805,089**	**5.6**	**$792,848,027**	**6.0**	**$937,155,255**	**18.2**

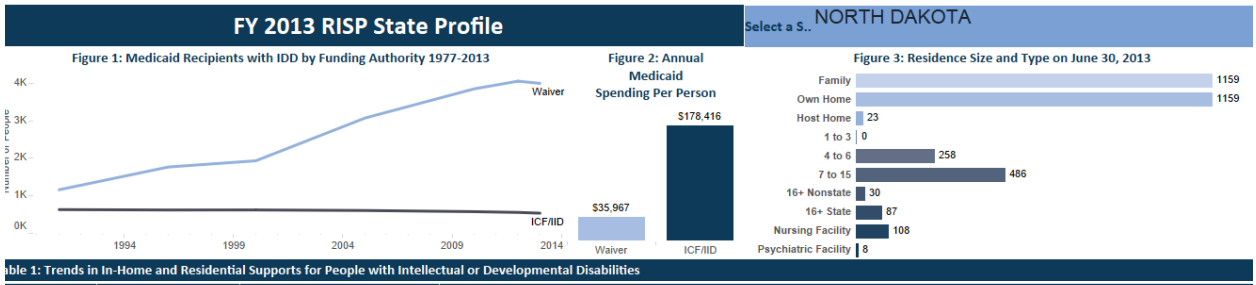
This data can also provide a strong baseline for states seeking to broaden the types of services and supports available within the state, or to begin offering new models of service delivery (such as developing or expanding authorities for HCBS).

Potential Coverage Gap Areas

<u>Supports for Individuals with I/DD</u>

As illustrated below, North Dakota's system of support for individuals with I/DD serves most individuals in their own homes or their family homes. The numbers of individuals served in HCBS appear congruent with the overall population of North Dakota and allow for a more than balanced approach in institutional versus community-based services. In fact, the state has seen double-digit growth in the HCBS waiver program for individuals with I/DD since 2011. The state's most recent CMS 372, which is a report that provides actual utilization and cost data to CMS on an annual basis also demonstrates that the most used services in the waiver are Infant Development. Given this early work with children and families and to ensure that the services available support individuals to remain in and thrive in their homes and communities, it may be beneficial to continue the work already underway to explore expanded options for in-home and community oriented supports and ongoing supports to families. North Dakota continues to grow opportunities for employment, a trend occurring in many states. Such an effort may entail the identification of newly available services and supports or a continuation of emphasis on those in-home, family-oriented services that are already available within the waiver program that may stave off the need for out-of-home services.

Exhibit 1[19]



able 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

etting Umbrella	Setting Type	Setting name	1977	1982	1987	1991	1996	2000	2005	2010	2013
ndividualized ettings	Individualized Settings	Own Home					882	966	1,070	1,267	1,159
		Family					2,098	393	569	907	1,159
		Host Home					42	38	27	27	23
		1 to 3						0	0	0	0
ongregate DD ettings by size nd type	4 to 15	4 to 6						201	192	251	258
		1 to 6	23	12	269	965	198	201	192	251	258
		7 to 15	47	146	702	595	503	495	536	487	486
	16+	16+ Nonstate				67	114	114	54	30	30
		16+ State				211	148	153	140	115	87
		16+ Total	1,306	1,076	1,412						
on-DD Specific	16+	Nursing Facility*				182	175	105	118	193	108
		Psychiatric Facility				1	0	0	0	0	8
eople with IDD i..	All Types	Waiting list					0	0	0	0	0
		Estimated Total, Residence Type Known	1,376	1,234	2,383	1,838	3,985	2,360	2,588	3,084	3,318
Medicaid ecipients and xpenditures	HCBS	Waiver Expenditures per Person				14,046	16,342	21,675	18,683	25,336	35,967
		Waiver Recipients per 100,000				27	277	302	483	573	553
	ICF/IID	ICF/IID Expenditures per Person*				64,077	70,090	79,969	107,014	155,783	178,416
		ICF/IID per 100,000*				100	98	97	96	86	75

Data for FY2013 may be from an outside source for these data elements. For ICF/IID expenditures and number of people, the source would be Eiken et al (2015). For Nursing Facilities, the source would be AHCA (2013a), (2013b), or (2013c).

[19] Larson, S.A., Eschenbacher, H.J., Anderson, L.L., Taylor, B., Pettingell, S., Hewitt, A., Sowers, M., & Fay, M.L. (2017). In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2014. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. Access at https://risp.umn.edu/publications

This snapshot of the I/DD service delivery system is reflective of individuals currently served, and therefore, those determined eligible to receive I/DD services and who meet level of care. There are often, as described above in the eligibility section, individuals who, though they may have a diagnosis of an I/DD, do not meet criteria related to functional limitations for eligibility. Though these individuals do not meet requirements for level of care, they may have needs for some ongoing supports and services. Included in the ***Recommendations for Consideration*** section are potential options for the State to consider to provide some limited services for this group (and potentially others as identified below).

For individuals with complex medical conditions or complex behavioral conditions, states are continually working to identify successful models of service delivery. For individuals with complex medical conditions, states have reviewed nurse practice act requirements to ascertain which, if any, functions can be performed and/or delegated in a community-based environment. States have also sought to continually build capacity within the state's service infrastructure to better meet the needs of individuals requiring medical supports. This may entail provider capacity building and recruitment, payment structure modifications to incentivize providers to gain the necessary skillset to support individuals with complex conditions. States are also exploring integrated models of support, such as health homes, to ensure that there is a comprehensive team available to design a coordinated approach to community based, medical and behavioral supports.

In addition, a number of states have been increasing their own capacity to understand the health status (including changes in health status) of individuals supporting, enabling an early indication of needed supports, services or other interventions. Georgia, Maryland and others are utilizing the Health Risk Screening Tool, and other states have incorporated health screening mechanisms into their ongoing oversight and monitoring strategies.

Supports for Individuals who are Aging and Individuals (adults) with Physical Disabilities

As noted above, North Dakota operates two HCBS waivers. One is targeted to individuals who are aging and individuals with physical disabilities and the other is targeted to individuals who are technology dependent. In addition to these waiver programs, individuals who are aging and individuals with physical disabilities are able to access services through the Medicaid State plan (case management, personal care, etc) and through two state-funded programs (SPED and Ex-SPED).

On the HCBS Medicaid Waiver (0273), the FY 15 CMS 372 report reveals very low service utilization for almost all services with the exception of case management. In addition, the unduplicated capacity (and the recorded unduplicated participant count for FY 15) appears low compared to states of comparable population. In fact, the proportion of LTSS expenditures in North Dakota's Aged/Physical Disability services is roughly 7% for HCBS and 93% institutional (nursing facility). Nationally, HCBS comprised 44 percent of FY 2015 LTSS expenditures for

this group. These proportions do not include the state funded resources available, so the percentage overall for HCBS will be higher when factoring in that level of support.

North Dakota may find it advantageous to seek opportunities to expand the understanding of key stakeholders about the availability of home and community based services, including outreach in nursing facilities, among case managers and others who could be key informants to individuals requiring long term services and supports.

In addition, as noted above, the State may wish to build in opportunities to determine whether additional of different service arrays would better meet the needs of constituents, both current enrollees as well as potential future enrollees. With the wide array of potential support needs of individuals eligible in the waiver, it may be beneficial to ascertain whether additional or different services (or modifications to existing services) may be advisable. States serving multiple, diverse groups of individuals often find it beneficial to ensure some specialty services are included. While a state cannot target a specific service to a subgroup of waiver enrollees, they may limit the service to only those who have a medical necessity for the service, naturally targeting the benefit. As an example, a number of states aging/physical disabilities waivers cover cognitive rehabilitation services. This service is largely only beneficial for individuals recovering from a brain injury, so the addition is both extremely valuable to certain individuals in the waiver while retaining low utilization due to the specific medical necessity criteria.

North Dakota also offers waiver services to individual who are technology dependent. The enrollment in this waiver is low as compared to similar waivers nationally, so the considerations noted above regarding outreach may also benefit this program.

Supports for Other Individuals with Disabilities

For the waivers that are designed to support children, North Dakota, like many states, is currently undergoing the exercise of determining what services should be included in the waiver that are truly over and above that which should be available to children through the EPSDT benefits. For all Medicaid beneficiaries, but especially for children, it is critical to consider the entirety of the state plan benefits available. North Dakota's Autism waiver is slated to have a significant increase in capacity, expanding the number of children receiving HCBS in addition to the anticipated state plan benefits.

It is essential that all operating agencies work closely with the State Medicaid Agency to understand both the coverage and access considerations of all state plan benefits to gain an accurate understanding regarding the availability of the service statewide.

North Dakota has already undertaken a significant amount of work to identify gaps and propose solutions to service availability for individuals with medically fragile conditions. Some states have enabled greater utilization of such programs by including more than one level of care for these types of waivers (including, for instance, nursing facility and ICF/ID to enable a broader

base of individuals to receive supports and, in many instances, to increase the cost comparison to enable sufficient community support in the waivers.

Supports for Individuals with Mental Health Support Needs and Individuals who do not Meet Level of Care

In most states, as is the case in North Dakota, there are often limited, if any, HCBS available for individuals with mental health support needs beyond the supports and services available to individuals through the Medicaid State Plan. This is due in large part to the fact that individuals with mental health support needs often do not meet the level of care requirements for one of the eligible Medicaid-financed institutional comparisons.

This is a similar case for individuals who do not meet an institutional level of care, even if they have a diagnosis of I/DD, who may be aging or have a physical disability. As noted above, the criteria can and should be applied in a manner that considers "but for the availability of supports, the individual *would* require an institutional level of care." Even with that application, however, some individuals are deemed ineligible for HCBS.

Certainly, maximizing access to the existing state plan benefit is an important first step. However, numerous other states are considering leveraging new Medicaid authorities to address potential gaps after a targeted identification of needs and service gaps.

***Perspectives* from Stakeholders**

In follow up to a survey sent to a broad array of stakeholders related to eligibility, access and services in North Dakota (with responses from 325 individuals, the state held statewide stakeholder advisory meetings on June 13, 2017 and on June 29, 2017. Both the survey and the stakeholder meetings provided valuable information and recommendations related to overall service delivery system in the State.

Below are broad themes that emerged from this information. The recommendations for consideration included in the subsequent sections were significantly informed by this valuable input:

1. Communication, Education and Information Sharing

   Numerous comments pointed out, either directly or through an apparent lack of understanding of the various services available, that one area of need in North Dakota relates to the availability of comprehensive, statewide information on supports and services for individuals who are aging and individuals with disabilities (including mental health supports). While there was a recognition of the potential county variations, there

seemed to be an overarching need among stakeholders and state staff alike for an easy-to-understand service mapping with access and points of contacts identified. Individuals expressed hope that, upon intake, they would have a full understanding of the array of supports and services potentially available.

In addition, stakeholder expressed interest in establishing pathways for connecting individuals and families together. There were also strong recommendations to simplifying and making very clear the entire eligibility application process.

2. Coordination and Meaningful Access to State Plan Services

In the context of transportation, autism services and mental health support services, participants in both the survey and public listening sessions revealed challenges and concerns with the ability to access (and receive in a timely manner) state plan services. Some of the services mentioned were recently removed from the waiver in the negotiations with CMS on the EPSDT compliance, but the availability, type, flexibility and sufficiency is reportedly feeling curtailed to some stakeholders. Individuals expressed an interest in making sure that the historic flexibility and responsiveness be retained in the move from the waiver to the state plan. In addition, in line with number 1 above, individuals seemed unaware of the best manner of access (and timely receipt of) state plan benefits.

3. Eligibility and Access

The survey indicated that only half of the respondents experienced challenges with the eligibility process, however, the comments and the subsequent discussions at the stakeholder meetings revealed concerns in the following areas:

- Uneven understanding and application of the standards and procedures at the county level of the statewide programs and eligibility requirements (both financial and clinical).
- For children, inconsistent application of I/DD eligibility criteria or delays in service access, or inappropriate/non-developmentally sensitive criteria for eligibility determination
- Concerns that certain diagnosis, even when there are significant functional limitations, are left without support
- Concerns that certain individuals with autism or other developmental disabilities are not able to effectively access key supports, such as employment
- Concern that children are unable to access Medicaid if they are ineligible for a waiver – recommendations related to Katie Beckett/TEFRA eligibility.

4. Array of Services

Individuals and families expressed concern that certain services were not available in some programs. For example, individual noted that services in the aging/physical disability waiver were not meeting needs of eligible individuals in that waiver with brain injury (and the provider qualifications were similarly mismatched).

There was concern/misunderstanding regarding the criteria and availability of respite services across the state.

Multiple individuals noted that the supports and services available to individuals with mental health needs (or individuals with co-occurring MH/IDD) were not sufficient to meet the need.

Recommendations for Consideration and Opportunities for Simplification

Fuller Discussion Contained in Content Above

ELIGIBILITY

- ***North Dakota could establish a clearer category perhaps just stating as many states do, the individual for purposes of eligibility must have an intellectual disability, and/or a developmental disability***
- ***In terms of assessing related conditions, the question may not be the severity of an intellectual disability, but the person's functional status—and the age of onset of the limitations. North Dakota may consider that an individual with borderline ID could meet related conditions if they have functional limitations and require treatment or supports similar to those provided to individuals with ID.***
- ***Most states do not ascertain related conditions eligibility using exhaustive diagnoses lists. States do specify a few diagnoses as meeting related conditions. These are meant to be illustrative/common examples and not a list for exclusionary purposes or to presuppose the outcomes of functional limitation assessment.***
- ***If North Dakota seeks to serve ONLY individuals with I/DD, there are some states that indicate individuals with related conditions but no intellectual disability and the capacity to oversee and manage their own services are not included in their eligibility for HCBS waivers serving individuals with ID/DD. This exclusion may include for example, individuals with cerebral palsy or epilepsy and no cognitive impairments who can manage their own planning. These individuals would be served on programs intended for individuals with physical disabilities as their needs may more closely align with the supports and services afforded individuals with physical disabilities.***

- ***Unless the individual clearly meets the ID criterion (and needs services), the process for assessment and determination of a related condition should be invoked for individual with cognitive impairment other than ID.***
- ***For children's eligibility:***
    - ***specify the assessments to assure they are valid and reliable tools that are properly normed on the population you intend to serve.***
    - ***In many states, the criteria for the Part C 0-3 program make sense as an eligibility platform for children 3. Part C under 'reframes' the lifelong criterion and states, "….(i) Has a high probability of resulting in developmental delay;…"[20]. North Dakota has an excellent 0-3 guide that might be useful.[21] For older children, measuring functioning against developmental stages at perhaps more frequent intervals than annually may satisfy concerns.***
- ***The initial eligibility assessment, Gollay Grid and PAR appear to collect much of the same information in different formats. We strongly suggest that the state, for adults, adopt one comprehensive assessment that can be used to ascertain "system" eligibility and level of care.***
- ***The state could analyze eligibility determination data to ascertain if a significant number of "system' eligibles individuals do not meet LOC. If so, this would suggest that screening for LOC remain separate from system eligibility screening. Conversely if there is a high correspondence between LOC and system eligibility, the state may opt for one eligibility assessment tool/process.***
- ***ND may wish to amend the LOC and active treatment guidance to reflect the CMS letter. Additionally it is worth remembering that the HCBS waiver LOC for ICF/IID is based on a 1981 standard. At that time individuals were provided institutional services (as these were typically what was available, who now, because of the HCBS waiver would not be institutionalized.***
- ***Review tools and process to ensure equal application across all target groups served or potentially served in the waiver. Review historical documents and processes to ascertain whether certain elements could be reintroduced to ameliorate this concern***.
-

SERVICE ARRAY AND AVAILABILITY

- ***Review full array of waiver processes and practices to streamline service access and system operations wherever possible (remove redundancies in eligibility as well as service authorizations and any other area of operational***

[20] § 42 CFR 303.21 Infant or toddler with a disability.
[21] Birth to 3 Early Learning Guidelines, ND DHS: https://www.nd.gov/dhs/info/pubs/docs/cfs/2009-08-earlylearning-birth-3.pdf

practice). Consider lean, standard operating protocol for county partners to increase consistency and information across the state.

- ***Engage in a systemic communication effort to ensure easy-to-understand information for internal and external stakeholders. Ensure full understanding of available services (promoting those that are likely to increase community integration, autonomy and choice).***
- ***Build strong pathways, partnerships and information to ensure smooth transition (at age 3, transition from school, etc).***
- ***Continue ongoing efforts with State Medicaid officials to ensure seamless access and information sharing between waiver and state plan benefit. Provide technical assistance to Medicaid staff to enhance flexibility and service usability for individuals with disabilities and their families.***
- ***Engage in efforts to ensure adequate supports for individuals with significant medical supports including;***
    - ***Consider adding services or exploring services/authorities to ensure strong coordination between health and community supports***
    - ***Ensure that any disincentives (financial, risk assumption) are mitigated to maximize provider/community capacity to serve individuals with complex needs***
    - ***Consider assessment/surveillance strategies to gain a strong understanding of health status among individuals served.***
- ***Implement recommendations related to Medically Fragile waiver to ensure adequate capacity for individuals with significant medical support needs. If cost limits are of concern, consider additional level of care strategies.***
- ***After determinations related to eligibility (level of care, etc), explore the development of a cross-disability 1915(i) HCBS program that could provide key HCBS (such as extended employment supports) to individuals with mental health support needs and individuals with disabilities who do not meet level of care.***
- ***Engage in significant efforts to expand use of both state-funded and Medicaid funded HCBS as alternatives to nursing facilities.***
- ***Establish and maintain HCBS advisory council comprised of individuals receiving services, families, advocates, providers and other key stakeholders to provide ongoing input on service design and delivery innovations***
- ***Institute regular and predictable methods of assessing sufficiency of capacity across waiver programs.***
- ***Establish state-level partnerships with public housing entity to expand availability of affordable, accessible housing options.***
- ***Leverage all learning and ensure sustainability of success of Money Follows the Person Demonstration, integrating practices into ongoing operational efforts.***

PERSON-CENTERED PLANNING

- ***North Dakota would benefit from a review of the required planning assessment tools in order to identify opportunities to streamline the process and the lessen number of tools required to be updated on an annual basis.***
- ***North Dakota DD agency should examine their current OSP template to look for opportunities to streamline information around health and welfare based on the person's individual needs and preferences so that individualized information regarding service and supports needed for each person to accomplish personal goals can be included in the plan to ensure true person centered planning.***
- ***North Dakota should consider investing in some type of person centered planning training for all the people responsible for the development of the OSP.***
- ***North Dakota would benefit from a review of the HCBS Assessment in order to identify opportunities to streamline the process focus the discovery process on information needed to develop a person-centered plan that identifies each person's goals and outcomes and the supports and services needed to attain those goals.***
-