PASRR and Related Conditions

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Objectives

- Describe how PASRR applies to persons with mental illness, intellectual disabilities and related conditions
- Describe the PASRR definition of related conditions
- Describe the current thinking about mental retardation versus intellectual disabilities, related conditions and developmental disabilities
- Describe the application of PASRR and its focus on functional limitation rather than intellectual deficits in determining appropriate placement and service delivery
- Describe “best practices” for determining appropriate placement and service delivery, as a result of a Level II PASRR evaluation

The Purposes of PASRR-#1

42 CFR 483.102, Applicability and Definitions

To ensure that individuals are evaluated for Evidence of possible mental illness (MI) and/or Intellectual disabilities and related conditions (ID/RC)

- PASRR Level I identifies which individuals will be evaluated
- PASRR Level II evaluates and confirms or disconfirms the diagnoses and applicability under PASRR-based on a comprehensive array of evaluations and related documentation

The Purposes of PASRR-#2

42 CFR 483.106, Basic Rule, 483.122, FFP for NF Services, 483.126, Appropriate Placement

To ensure that the PASRR-related individuals are placed appropriately in the least restrictive setting possible

- A nursing facility shall not admit on or after January 1, 1989 any new resident with mental illness or with intellectual disabilities/related conditions unless s/he is determined to be appropriate for nursing facility services
- FFP (Federal Financial Participation) is available only for services furnished after compliance with PASRR

The Purposes of PASRR-#3

42 CFR 483.106, Basic Rule

To recommend that the PASRR-related individual receive the services that s/he needs, wherever s/he is placed

- Placement in a nursing facility is appropriate only when the individual's needs meet minimum standards for admission and when his/her need for treatment does not exceed the level of nursing facility services, either through nursing facility services alone or with additional specialized services

The Purposes of PASRR-#4

Title II, ADA 1990

That no qualified individual with a disability shall be excluded from participation in or be denied benefits of services, programs or activities in the most appropriate setting that meets his/her needs

The Purposes of PASRR-#5

Olmstead v LC and LW 1999

To reflect the intentions of the Olmstead v LC/LW (two individuals with mental disabilities in Georgia state-run psychiatric hospital) 1999 decision:

- Which enforced the principles of the Americans with Disabilities Act
- Which ensured that individuals with disabilities have the right to live independently

The Purposes of PASRR-#6

To Continue the Culture Change by Utilizing the Power of PASRR

- PASRR is (and always has been) a powerful tool for diversions and transitions from institutions and for making individuals with disabilities aware of alternatives
- The Level II PASRR evaluation identifies person-centered recommendations that become part of the nursing facility plan of care that addresses ALL of the PASRR-related individual's needs OR that identifies and facilitates community-based least restrictive alternatives

A Few Obvious Preliminaries-#1

- Medicaid is a partnership between the states and the Federal Government

A Few Obvious Preliminaries-#2

The services provided by the state are identified in the Medicaid State

Plan (42 CFR 483.104, State Plan Requirement)

- Medicaid covers mandatory services, e.g., physician services, hospital services, family planning services and nursing facility services (including specialized rehabilitative services, which are services provided by the nursing facility to only individuals with MI, ID/RC, and are less intense than specialized services)
- Medicaid allows states to select optional services such as personal care services, prescription drugs, rehabilitative services, therapies (physical, occupational, speech, etc.), and if provided, must be provided to all Medicaid clients
- Special Medicaid programs (either through waiver programs or as state options) limit coverage to selected services to selected groups in selected locations

A Few Obvious Preliminaries-#3

- PASRR is a requirement under Medicaid, pursuant to OBRA1987 (Omnibus Budget Reconciliation Act) and 42 CFR 483.100-483-138
- PASRR-related individuals are subject to the state's Medicaid requirements and to PASARR
- PASRR is meant to bar admission to a nursing facility for any individual with MI or ID/RC if the nursing facility cannot meet the individual's total needs for nursing facility services and specialized services
- PASRR creates a partnership between Medicaid, the states' MI and ID/RC agencies, state licensure, the nursing facilities, and community-based providers

A Few Obvious Preliminaries-#4

- State MI and ID/RC agencies operating under the state's Medicaid authority are responsible for ensuring PASRR's compliance
  - Consider written memorandums of understanding to spell out roles and responsibilities
- PASRR Determinations made by the state's MI and ID/RC agencies cannot be countermanded by the state Medicaid agency; however, determinations must be consistent with criteria adopted by the state Medicaid agency and the state plan (42 CFR 483.108, Relationship of PASRR to other Medicaid Processes)

A Few Obvious Preliminaries-#5

- As a requirement under Medicaid, PASRR-related activities are reimbursable at 75% Federal Financial Participation (FFP) for administrative functions
- Nursing facility level of care determinations are reimbursable at 50% FFP unless integrated with PASRR
  - July 9, 2013 National Association of PASRR Professional (NAPP) webinar will cover the 75%/25% PASRR rule

A Few Obvious Preliminaries-#6

42 CFR 483.122, FFP for NF services
42 CFR 483.124, FFP for Specialized Services

- FFP is available for nursing facility (NF) services if the individual is determined to need NF services, with or without the need for specialized services
- FFP is available for NF services if the individual is determined to not need NF services but to need specialized services and elects to stay in the NF, if the "choice" applied/applies
- FFP is available for NF services only if PASRR is completed prior to admission; a PASRR screening completed after admission or for a resident review that isn't timely is only available for services after the review is completed
- FFP is not available to specialized services furnished to NF residents as NF services, but is covered as an extension to the NF package of services

A Few Obvious Preliminaries-#7

- In many cases, a nursing facility is the best way to care for an individual with MI or ID/RC with a chronic illness but the nursing facility is not always equipped to meet the ALL of the needs of individuals with MI or ID/DD
- PASRR is a way to assist the nursing facility in meeting ALL of the PASRR-related individual's needs
- PASRR is a way to identify alternatives to the nursing facility, such as home and community-based services; however, PASRR does not necessarily improve access to HCBS services
- PASARR is tied to Money Follows the Person (MFP) and is a gateway to community services

A Few Obvious Preliminaries-#8

- PASRR applies to all individuals applying to Medicaid certified nursing facilities (on or after January 1, 1989)
  - That is, distinct parts of facilities, or dually certified Medicare/Medicaid facilities or distinct parts, or Medicaid-certified or dually certified beds
- PASRR applies regardless of payment source (Medicaid, Medicare or private pay)
- PASRR is an issue of licensure for the nursing facility, and should involve monitoring by the state licensure/compliance entity

A Few Obvious Preliminaries-#9

- PASRR inherits all the requirements of Medicaid (facility definitions & certifications, fair hearing, etc.)
- PASRR requires common elements but allows for state variations:
  - Development of forms, processes, training, guides, etc.
  - Personnel qualifications
  - Selection of options
  - Timing of level of care determinations
  - Provision of Specialized Services (however, this is changing)
- States can exceed Federal requirements but must meet minimum requirements

Key Milestones in PASRR & Related Efforts

Legal/Regulatory Milestone	Act	Year
Establishment of Title XIX (Medicaid), requiring states to comply with elements of its state plan	SSA	1965
Creation of 1915(c) HCBS waivers, allowing states to waive certain statutory requirements (comparability, state-wideness and freedom of choice) and establish cost-effectiveness measures and access to services not otherwise available to the "waiver" population •1915 a (voluntary contracted managed care provision of state plan/HCBS services •1915i (HCBS as a state plan option) •1932a (state plan option for mandatory and voluntary managed care on a statewide or limited geographic basis) •1915b (mandatory managed care) •1115 Demonstration for community-based programs	SSA	1981

Key Milestones in PASRR & Related Efforts

Legal/Regulatory Milestone	Act	Year
Establishment of *PASRR*	OBRA	1987
Required start of PASRR	OBRA	1989
Americans with Disabilities Act (ADA), requiring service delivery in the most integrated setting	ADA	1990
Publication of PASRR Final Rule		1992
Incorporation at 42 CFR 483.100-138		1994
Elimination of Annual Resident Review, changing acronym from PASARRP to PASRR	BBA	1997

Key Milestones in PASRR & Related Efforts

Legal/Regulatory Milestone	Act	Year
Olmstead v. L.C. and L.W, enforcing ADA and preventing institutionalization and least restrictive alternatives	--	1999
Establishment of 1915(j), 1915(i), Money Follows the Person •1915j, giving individuals power to self-direct personal assistance services •1915i, allowing states to provide HCBS based on needs-based criteria rather than diagnosis and to individuals whose needs to not necessarily rise to an institutional level of care	DRA	2005
AAMR changed it name to American Association of Intellectual Disabilities		2007

Key Milestones in PASRR & Related Efforts

Legal/Regulatory Milestone	Act	Year
Changes to 1915(i), creation of 1915(k), more Money Follows the Person •State plan option to provide home and community-based attendant services and supports	ACA	2010
Roll-out of MDS 3.0 with Q.A1500 and new Section Q •Change from version 2.0 to 3.0 •Reliance on MDS, which is completed for every resident in a Medicaid-certified nursing facility; completed within 14 days of admission, quarterly, annually and upon a significant change; used in care planning and to establish payment	--	2010
PASRR Self-Assessment Tool Created		2010
Formation of PTAC		2010
PASRR Self-Assessment Tool Revised		2013
Clarification of Specialized Services		2013

The PASRR Process-The Level I Screen

The Level I Screen:

- Identifies who has or may have (that is, looking beyond a known diagnosis) mental illness, intellectual disability, or a related condition
- Should cause for a Level II Evaluation to be completed if there is a diagnosis or if there is an indication or suspicion of a diagnosis

The PASRR Process-The Level I Screen

The Level I Screen:

- May be developed by the state as long as the outcomes are shown to be accurate and the tool itself:
  - Is based on documented training and established processes
  - Provides for a sufficient-enough review of documented evidence to determine whether a Level II Evaluation is required or whether exclusions or categorical determinations apply

The PASRR Process-The Level I Screener

- The qualifications for who can conduct a Level I Screen may be determined by the state as long as the state:
  - Provides written procedures, specified forms and training
  - Maintains responsibility for the accuracy of the screens
- States may use hospital staff, specialty-trained Level I Screeners or may use persons who are qualified as Level II Evaluators
- States are not prohibited from using nursing facility staff to complete the Level I Screen but this is not considered "best practice" and requires careful monitoring

The PASRR Process-The Level I Screener

The Level I Screener:

- Does not typically have expertise with MI, ID/RC
- Does not typically make or verify a diagnosis or draw conclusions about severity of illness, whether dementia is primary, or whether the person needs services
- Typically, looks for available information and assessments made by other qualified persons to determine:
  - If the documented evidence is sufficient enough to rule out the diagnosis of MI, ID/RC; if not, s/he may stop further review
  - If the documented evidence is sufficient enough to apply certain pre-determined criteria (i.e., exemptions, exclusions and categorical determinations)
  - If a Level II Evaluation is required

The PASRR Process-The Level II Evaluation

The Level II Evaluation is an in-depth determination that:

- Confirms or disconfirms a diagnosis
- Identifies/recommends appropriate treatment/placement options and services
- Is based on state-selected tools, as long as the tools are validated and achieve the required outcomes
- Is completed within an annual average of 7-9 working days of when the Level I Screen is completed and a referral is made , unless an exception is granted (by CMS)
- Is adapted to culture, language, and ethnic origin
- Involves the individual, family/legal representative and ensures interdisciplinary coordination

The PASRR Process-The Level II Evaluation

When determining nursing facility and specialized services for an individual with MI:

- The determination must be made by the state MI authority and must be based on an independent physical and mental evaluation performed by a person or entity other than the state MI authority
- The state MI authority only has responsibility for the determination function and therefore cannot delegate the evaluation function; therefore, the evaluation function must be performed by a person or entity other than the state MI authority

The PASRR Process-The Level II Evaluation

When determining nursing facility (NF) and specialized Services for an individual with MI:

- The state MI authority shall:
  - Retain ultimate control and responsibility for the performance of their statutory obligations
  - Ensure the two determinations are made and based on consistent data, and
  - Ensure the entity to which the delegation is made is not a NF or an entity that has direct or indirect affiliation or relationship with a NF

The PASRR Process-The Level II Evaluation

When determining nursing facility and specialized services for an individual with ID/RC:

- The evaluation and determination must be made by the state ID/RC authority
- The state ID/RC authority may delegate by subcontract the evaluation and determination functions to another entity if:
  - They retain ultimate control and responsibility for the performance of their statutory obligations
  - The two determinations are made and based on consistent data, and
  - The entity to which the delegation is made is not a NF or an entity that has direct or indirect affiliation or relationship with a NF

The PASRR Process-The Level II Evaluation

- The Level II Evaluation is an integral part of the individual's plan for services (regardless of where s/he is placed)
- If at a nursing facility, the Level II Evaluation/Report is incorporated into the routine resident assessments (Resident Assessment Instrument(RAI)/Minimum Data Set(MDS)) and becomes part of the individualized interdisciplinary plan of care

(Resident Assessment Instrument(RAI)/Minimum Data Set(MDS))

- Initial admission (within 14 days of admission)
- Resident Assessment Protocols/RAPs (within 14 days of admission
- Plan of care within 21 days of admission or within 7 days of completion of MDS/RAPs
- Quarterly assessments within 92 days of the previous assessment along with care plan review
- Annual assessment with RAPs within 366 days of the previous full assessment along with care plan review and updates
- Significant Changes in Status/Significant Correction
- Discharge Tracking within 7 days of D/C
- Re-entry tracking within 7 days of readmission after a D/C return anticipated

The PASRR Process-The Level II Evaluation Report

The Level II Evaluation Report (individualized or abbreviated) is a comprehensive assessment and:

- Is completed prior to admission
- Must summarize information about the individual and identify supportive documents by type and date
- Is written in a manner that assists with care/service planning for the individual
- Recommends treatment options/placement options
- Must be interpreted and explained to the individual

The PASRR Process-The Level II Evaluation Report

The Level II Evaluation Reports for a person with MI addresses and summarizes the following information:

- H&P (including all body systems, neurological and other specialty evaluations) performed by a physician
- a comprehensive drug history including current or recent use of medications that could mask symptoms or mimic symptoms
- a comprehensive psychosocial evaluation including current living arrangements/medical/social supports

The PASRR Process-The Level II Evaluation Report

The Level II Evaluation Reports for a person with MI addresses and summarizes the following information:

- a functional assessment including ADLs and IADLs (including self-monitoring of health status, self-administration and scheduling of medical treatment and medications, self-monitoring of nutritional status, ability to handle money and ability to groom and dress appropriately)
- assessment of level of support for ADLs needed in an alternative community setting or in a NF
- an assessment of psychiatric history (including evaluation of intellectual functioning, memory functioning, orientation, current attitudes and overt behaviors, paranoia, affect, suicidal/homicidal ideations and degree of reality testing and hallucinations) for MI performed by a qualified psychiatrist, psychiatric social worker, or a nurse with substantial psychiatric experience

The PASRR Process-The Level II Evaluation Report

The Level II Evaluation Reports for a person with ID/RC addresses and summarizes the following information:

- Comprehensive H&P sufficient to assess individual's medical problems and impact on the individual's independent functioning
- All current medications and current response to hypnotics, anti-psychotics, mood stabilizers and anti-depressants, anti-anxiety sedative agents and anti-Parkinson agents
- An assessment of IQ performed by a qualified Psychologist for ID

The PASRR Process-The Level II Evaluation Report

The Level II Evaluation Reports for a person with ID/RC addresses and summarizes the following information:

- Self-monitoring of nutritional status, health status
- Self-help development such as toileting, dressing, grooming and eating
- Self-administering and scheduling of medical treatments
- Sensorimotor development and extent to which prosthetic, orthotic, corrective or mechanical supportive devices can improve the person's functional capacity
- Speech and language (communication) development

The PASRR Process-The Level II Evaluation Report

The Level II Evaluation Report for a person with ID/RC addresses and summarizes the following information:

- Social development such as interpersonal skills, recreation-leisure skills, and relationships with others
- Academic/educational development, including functional learning skills
- Independent living development such as meal preparation, budgeting, survival skills, mobility skills, laundry, housekeeping, shopping and bed making
- Vocational development
- Affective development such as interests, making judgments, expressing emotions and making independent judgments
- Presence of identifiable, maladaptive or inappropriate behaviors

The PASRR Process-The Level II Evaluation Report

- The Level II Evaluation report must also include the applicable specialized services, and identify where these services are available

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The PASRR Process-The Level II Evaluation Report

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The PASRR Process-The Level II Evaluation Report Applicable References

- 42 CFR 483.116, Residents and Applicants Determine to Require NF LOC
- 42 CFR 483.132, Evaluating the need for NF services and NF Level of Care (PASRR/NF)
- 42 CFR Part 440-Subpart A-Definitions
- 42 CFR 440.180, HCBS
- 42 CFR Part 441-HCBS Waiver Requirements
- 441.300, Basis and Purpose

The PASRR Process-Options

Acute Inpatient

- Individual’s needs are acute enough that they require treatment in a acute setting, e.g., Institution for Persons with Mental Disease (IMD), Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID), formerly ICF/MR, or other inpatient hospital

The PASRR Process-Options

Nursing Facility-Basic Package of Services

- An individual with MI or ID/RC must meet the minimum requirements to be admitted to a nursing facility, based on the state's level of care definitions
- MI or ID/RC alone is not enough to warrant admission to a NF
- Admitting an individual with MI or ID/RC whose needs do not rise to the level of NF is a violation of Olmstead

What about Level of Care (LOC)?

The PASRR Final Rule (1992) contemplated that Level of Care would be integrated with PASRR

- PASRR requires a collaboration between the nursing facility, Medicaid, and the MI and ID/RC authorities in providing nursing facility and specialized services
- The Level II Evaluation should address the need for nursing facility placement/services and specialized services, and all recommendations should be incorporated into the plan of care
- The provision of care is implemented by the nursing facility, in conjunction with the PASRR professionals, and monitored through licensure and compliance
- While nursing facilities may not participate directly with PASRR, the nursing facility should make an informed decision about admission

The PASRR Process-Options

Nursing Facility-Basic Package of Services

- Individual's needs (medical, MI-related, ID/RC-related) must be severe enough to require basic nursing facility services as part of the standard per diem and typically provided by nursing facility staff, to include:
  - 24 hours of skilled nursing care
  - Rehabilitative (medical or remedial for maximum reduction of physical/mental disability or restorative in nature to the best possible functional level)
  - Specialized rehabilitative services (specific to an individual resident with MI or ID/RC and not all residents, and less intense than specialized services)

The PASRR Process-Options

Nursing Facility-Basic Package of Services PLUS

- Individual's needs require nursing facility services plus specialized services, which are in addition to the standard nursing facility package of services and standard per diem
- State defines where nursing facility services stop and specialized services begin
- A list of "what services are familiar to the state" is acceptable but does not rule out the possibility of other "individualized services" as defined by PASRR
- Moving an individual to an IMD or ICFIID is not an option

The PASRR Process-Options

Nursing Facility-A Few Other Considerations

- State must provide assurances that the nursing facility and it's staff can provide the specialized rehabilitative services and arrange for specialized services
  - Consequently not all facilities can meet the needs of an individual with MI or ID/RC
  - That is, a nursing facility placement is deemed appropriate only if the nursing facility has the ability and capacity to provide the necessary nursing facility services and specialized services to an individual with MI and/or ID/RC; a PASRR determination that NF is appropriate is "facility-specific"
- Monitoring plan of care would most logically fall to state survey agency, which can issue tags; No clear federal guidance on this issue; however, this is being addressed by CMS (in the meantime, talk to survey/licensure)

The PASRR Process-Options

Community

- Individual's needs allow for a less restrictive setting
- Typically, community-based services are provided through state-waiver services
- The individual may receive "community-based services" in the nursing facility, if these are considered "specialized services"
- Even if nursing facility is ultimately the most practical option, the Level II Evaluation should identify the services the individual would need to live in the community, even if those services do not exist or are inaccessible due to distance, lack of HCBS waiver or waiting lists….ultimately creating a "transition-out" list

Hierarchy of Services

PASRR must prioritize the physical and disability-specific needs of the individual, taking into account the severity of each condition and determine whether nursing facility placement is appropriate

Most Restrictive	Needs can only be met in an acute, inpatient setting such as an acute hospital, IMD or ICF/IID
	Needs can be met in a nursing facility, with additional specialized services
	Needs can be met in a nursing facility, with only nursing facility services and specialized rehabilitative services
Least Restrictive	Needs can be met in an appropriate community-based setting

Diagnoses: Mental Illness

Diagnosis	Make or confirm a diagnosis of major mental illness that is *not episodic/situational and that does not include a primary diagnosis of dementia* **Dementia will be discussed in more detail later*
Timing	Recent major treatment episodes *that are more intensive than outpatient care more than once resulting in partial or inpatient hospitalization* OR significant disruption *due to MI and requiring supportive services* within past 2 years
Disability	Active symptoms last 6 months *that results in functional limitations in major life activities:* • interpersonal functioning • concentration/pace/persistence • adaptation to change
Examples	(e.g., schizophrenia, bipolar disorder, major depression)

Diagnostic categories from DSM III-R, 1987 or most current diagnostic manual

Diagnoses: Mental Illness

- Diagnosis:
  - Based on standardized tests completed by qualified professionals (per state's scope of practice standards)
- Timing
  - To be relevant for PASRR, the duration is well-defined and qualifying treatment must have taken place within the last two years
- Disability
  - For PASRR purposes, a particular level of disability
  - The individual's mental illness results in functional limitation is major life activities within the past 3-6 months
  - The individual doesn't need to have been hospitalized or have seen a MH professional; it is the severity and recency of impairment that matters

Diagnoses: Mental Illness

Functional Limitations (in major life activities) appropriate for the individual's developmental stage and at least one of the following on a continuing or intermittent basis:

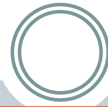
- Interpersonal Functioning: serious difficulty interacting or communicating effectively with possible history of altercations, evictions, social isolation, etc.
- Concentration, persistence and pace: exhibiting serious difficulty in sustaining focused attention in order to complete tasks commonly associated with work, home or school
- Adaptation to change: serious difficulty in adapting to typical changes in circumstances at work, home or school manifesting in agitation, withdrawal and requiring intervention

Diagnoses: Mental Illness

Applicability:

- States may create a broader definition for PASRR purposes as long as it does not conflict with the minimum federal standard
- Mental illness often accompanies other major health issues, e.g., heart, diabetes, liver, etc.
- Other diagnoses that may lead to a chronic disabling condition include mood, paranoid, panic or other severe anxiety disorders; somatoform disorders, personality disorders; other psychotic disorders, etc.
- The diagnosis of major mental illness as defined here is for PASRR purposes and may differ from definitions for other service eligibility programs; Some states utilize the PASRR process for waiver eligibility purposes

Diagnoses: Intellectual Disability (ID)
Previously referred to as mental retardation



Diagnosis	IQ < 70 per standardized, reliable test *and that measure capacity for learning, reasoning, problem solving, etc.*
Timing	Onset before age 18
Duration	Likely to be lifelong
Disability	Concurrent impairments in *adaptive functioning*

Criteria from AAIDD (formerly AAMR), 1983

Diagnoses: Intellectual Disability

- Diagnosis
  - Based on standardized tests completed by qualified professionals (per state's scope of practice standards)
- Timing
  - Substantiation of onset may be difficult to establish and may need to be based on other supportive information
- Duration
  - Likely to be lifelong
- Disability
  - Conceptual skills-language and literacy; money, time and number concepts; and self-direction
  - Social skills-interpersonal skills, social responsibility, self-esteem, gullibility, naiveté, social problems solving and ability to following rules, obey laws and avoid being victimized
  - Practical skills-ADLs (personal care), occupational skills, health care, travel/transportation, schedules/routines, safety, use of money and telephone

Diagnoses: Intellectual Disability (ID)

Applicability:

- States may create a broader definition for PASRR purposes as long as it does not conflict with the minimum federal standard
- ID often accompanies other major health issues, e.g., heart, diabetes, liver, etc.
- The diagnosis of ID as defined here is for PASRR purposes and may differ from definitions for other service eligibility programs; Some states utilize the PASRR process for waiver eligibility purposes

Diagnoses: Intellectual Disability

Intellectual Disabilities-A Few Considerations

- For PASRR purposes, the federal definition of mental retardation (MR) remains in the federal regulations.
- Mental Retardation is no longer a term used by the professional organization formerly known as the American Association of Mental Retardation (AAMR).
  - The organization is now known as the American Association on Intellectual and Developmental Disabilities (AAIDD).
- The term "intellectual disability" is the correct, current term.
- Intellectual disability is defined by AAIDD as "a disability characterized by significant limitations both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior (range of social and practical skills), and which originates prior to the age of 18

Related Conditions

Diagnosis	A severe chronic disability that is attributable to cerebral palsy or epilepsy or any other condition, other than mental illness, that • Results in similar impairment of general intellectual function or adaptive behavior similar to that of mentally retarded persons AND • Requires similar treatment or services
Timing	Manifested before age 22
Duration	Likely to continue indefinitely
Disability	Result in substantial functional impairments in 3 or more major life activities (e.g., self-care, mobility, understanding and use of language, learning, self-direction, capacity for independent living)
Examples	autism, cerebral palsy, epilepsy, TBI, fetal alcohol syndrome, muscular dystrophy, Down Syndrome (not an exhaustive list)

The language of the CFR is stated diagnostically, but the key is similarity in function.

Diagnoses: Related Conditions

- Diagnosis
  - For PASRR purposes, related conditions are conditions that are not necessarily a form of intellectual disability (i.e., mental retardation) but which often produce similar functional impairments and require similar treatment or services
- Timing
  - Substantiation of onset may be difficult to establish and may need to be based on other supportive information
- Duration
  - Likely to be lifelong
- Disability
  - Related because of similar impairments in intellectual functioning or adaptive behavior AND requires similar treatment and services

Considerations and Recommendations

- The Power of PASRR and Related Conditions
- Best Practices for Applicability of Functionality and Reasonable Approaches to Level I and Level II Determinations and Recommendations for Persons with Related Conditions

Developmental Disabilities

Developmental Disabilities…consider the applicable components of a more universal term (Developmental Disabilities Assistance and bill of Rights of 2000-Public Law 106-402)

- a severe, chronic disability that is attributable to a mental or physical impairment or combination of mental and physical impairments
- is manifested before the individual attains age 22
- is likely to continue indefinitely, and
- results in substantial functional limitations in 3 or more areas of major life activity (self-care, receptive and expressive language, learning, mobility, self-direction, capacity of independent living, economic self-sufficiency) and
- reflects the need for special, interdisciplinary, or generic or individualized supports of lifelong or extended duration and re individually planned and coordinated

Developmental Disabilities

- Some developmental disabilities can be strictly physical (with no intellectual disability), e.g., congenital deafness or visual impairments
- Some developmental disabilities may be caused by cerebral palsy, seizure disorder or autism and may include a intellectual disability
- Some developmental disabilities may be chromosomal disorders such as Down Syndrome, fetal alcohol syndrome, etc., and may include a intellectual disability but not always
- Some intellectual disabilities have no known cause

Developmental Disabilities

- Look beyond the condition and determine if the individual has impairments because of the condition
- Consider conceptual, social and practical skills such as interpersonal skills, social responsibility and social problem-solving, …beyond the areas of major life functioning
- Consider inability to function independently and require lifelong supports…and move away from “similar to that of persons with intellectual disability”
- Consider mental illness occurring during the developmental period

Mental Retardation

- The federal definition of 'mental retardation' has not been updated to reflect current clinical thought and practice. Since the term 'mental retardation is used as the basis for the definition of 'related condition,' updates to the definition of 'mental retardation' (in the context of recommendations related to changes in the definition of 'related condition') would also be necessary.

Mental Retardation

- "Mental Retardation" is no longer a term in use by the professional organization formerly known as the American Association of Mental Retardation (AAMR.) The organization, now known as the American Association on Intellectual and Developmental Disabilities (AAIDD), has adopted the term "Intellectual Disability." Intellectual disability is defined by AAIDD as "a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior, and which originates prior to the age of 18." (AAIDD)

Developmental Disability

- Over the course of the past 20 to 25 years, the term "developmental disability" has also come into common use. While there are numerous definitions of 'developmental disability,' the definition found in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (Public Law 106-402) defines the term as follows:

Developmental Disability

“In general, the term ‘developmental disability" means a severe, chronic disability of an individual that-

(a) is attributable to a mental or physical impairment or combination of mental and physical impairments;

(b) is manifested before the individual attains age 22;

(c) is likely to continue indefinitely;

(d) results in substantial functional limitations in 3 or more of the following areas of major life activity:

(1) Self-care.
(2) Receptive and expressive language.
(3) Learning.
(4) Mobility.
(5) Self-direction.
(6) Capacity for independent living.
(7) Economic self-sufficiency; and
(8) reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.”

Recommendations

- Since there has been so much change in the terms that are the basis for the definition of 'related condition,' relative change to how that term is defined must be made.
- At this time, the following recommendations are made to the PASRR regulations and/or applicability of how PASRR regulations are applied during the Level I and Level II processes:

Remove Categorical Diagnoses

- Removal of the categorical diagnoses of cerebral palsy and epilepsy which are considered related conditions if they are found to result in a severe, chronic disability
- Cerebral palsy and epilepsy may not result in impairment of general intellectual function or impairment of adaptive behavior, so for individuals with such a diagnosis, consideration of it as a condition related to mental retardation may be considered faulty

Use Intellectual Disability

- Adoption of the use and definition of 'intellectual disability,' rather than 'mental retardation,' which requires the existence of deficits in intellectual functioning as well as adaptive functioning
- Consider including conceptual, social, and practical skills that may not currently be considered in assessments that cover the 6 areas of major life functioning, such as interpersonal skills, social responsibility, and social problem-solving.

Move Away from Reference to Similarity with Mental Retardation

- Continue considering the presence of "impairment of general intellectual function OR [impairment in] adaptive behavior," but do not require that such impairment be "similar to that of mentally retarded [now, persons with intellectual disabilities.]"
- In the future, a person with a related condition, while not necessarily having deficits in intellectual functioning, may have adaptive behavior deficits that impede their ability to function independently and require lifelong supports

•As the country moves away from the ICF-MR model, the waiver of which is the basis for funding of community-based services for people with DD, consideration m

Developmental Disability

- Adoption of the term 'developmental disability,' of which 'intellectual disability' is just one type
- At this time, disability attributed to 'mental illness' is excluded from the definition of mental retardation and related conditions
- If the term developmental disability and its definition are adopted, consideration to inclusion of mental illness occurring during the developmental period may need to be considered

Future Recommendations

- Update the report entitled “State Strategies for Determining Eligibility and Level of Care for ICF/MR and Waiver Program Participants” that was completed in July, 2008, by the National Association of State Directors of Developmental Disabilities Services for the Rutgers Center for State Health Policy and the National Academy for State Health Policy
- Select a sample of states with similar and disparate definitions and interview representatives from these states

Additional Considerations

- Consider the following:
  - historical information about the state's definition
  - any problems, from the state's perspective, with the state's definition and how the definition affects eligibility for individuals with limitations
  - how the state views the definition of related conditions
  - how actual practices impact the application of the definition

Additional Considerations

- Consider the "clinical" view of related conditions from a sampling of clinicians we have worked with in the past who we feel are experienced in this area
- Identify leading practices and the impact of the definition of related conditions on eligibility, availability of services, level of care determinations and funding
- This may be anecdotal and not statistical in nature, and, may present additional issues in the interpretation of the information gathered
- Learn more about how the varying definitions and standards of practice utilized by different states impacts the outcomes of the need for service and supports

Additional Considerations

- Describe "best practices" for determining appropriate placement and service delivery, as a result of a Level II PASRR evaluation

Specialized Services

- 42 CFR 483.120, Specialized Services
- 42 CFR 483.134, Evaluating whether an Individual with MI requires SS (PASRR/MI)
- 42 CFR 483.136, Evaluating whether an individual with ID/RC requires specialized services (PASRR/MR)
- 42 CFR 483-Subpart I, Conditions of Participation for Intermediate Care Facilities

Specialized Services: Two Definitions

- **Definition 1:** Services provided to NF residents
  - Services provided to nursing facility residents beyond what the nursing facility provides under its per diem (e.g., day program, behavioral support)
- **Definition 2:** Services *not* provided to NF residents (i.e., provided in another context)
  - Community programs, including waiver programs
  - In-patient psychiatric
  - ICF/IID
- **CMS is moving toward Definition 1.**

Specialized Services

- Specialized services are services which when combined with nursing facility (NF) services result in a continuous and aggressive individualized plan of care that is developed and supervised by an interdisciplinary team that:
  - prescribes specific therapies and activities by trained MI or ID/RC personnel
  - is directed towards outcomes that increase functional level and reduce the need for specialized services and institutionalization

Specialized Services

"Specialized Services" Is:

- More than a list of services but are those services unique to the individual
  - States may identify commonly provided services
- Whatever disability-specific services a PASRR Level II individual uniquely needs
- The disability-specific services and supports that are above what a nursing facility provides as nursing facility services and nursing facility specialized rehabilitative services
- Delivered by providers who are specially trained and qualified to provide mental health or intellectual disability services; typically not by nursing facility staff

Specialized Services

Two New Proposed Coverage Options

- Option 1:
  - State defines specialized services that are billed separately by the nursing facility, separate from the standard nursing facility reimbursement
  - The NF contracts with specialized service providers, and the providers are paid by the NF
  - The NF bills the state Medicaid agency
  - The state Medicaid agency pays the NF

Specialized Services

Two New Proposed Coverage Options

- Option 2:
  - State defines specialized services that are billed separately by the NF, separate from the standard NF reimbursement
  - The specialized service provider bills directly to Medicaid

- CMS will roll-out this concept at the June 11, 2013 NAPP Webinar
- Both options will require further CMS directives, state plan amendments and changes in state billing procedures

Specialized Services

A few examples:

- Continuation of or development of an individualized plan for “habilitation”, skill development, behavior management, etc.
- Continuation with or development of a day or other vocational service program.
- Development and implementation of a positive behavior support plan, emergency safety interventions, and support/consultation to reduce negative behaviors, e.g., wandering/pacing, hitting, personal space, etc.
- Additional 1:1 with a qualified MI or ID/DD professional to work with the individual and the staff to maintain the person’s independence with choice, ADLs, other functional skills, etc.
- Additional 1:1 with a qualified MI or ID/DD professional to provide advocacy, mode of communication, communication with family, etc.

- Case Examples

Questions?

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