2014 PASRR National Report

A Review of Preadmission Screening and Resident Review (PASRR) Programs

PTAC
PASRR Technical Assistance Center

A joint partnership of
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Prepared for the Centers for Medicare and Medicaid Services

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Executive Summary

This third Preadmission Screening and Resident Review (PASRR) national report examines nursing home data and state Level I initial screening tools. Nursing home data indicates that in most states PASRR under-identifies individuals with serious mental illness, and to a lesser extent, intellectual disability. That data corroborates our finding that in most states the Level I PASRR initial screening tools do not contain all the necessary triggers to identify individuals who could have serious mental illness, intellectual disability, or a related condition, who should be fully evaluated by PASRR Level II. As the first analysis of state PASRR Level I methods, the report draws limited conclusions about any one state, but the need for system improvement nationally is evident. PTAC and CMS will work with states to better understand effective Level I methods and help them improve PASRR identification of vulnerable individuals.

Background

Individuals with mental illness, intellectual disability, or a related condition who require long term care have special protections under PASRR in Medicaid law to ensure that long term services and supports are provided in the most integrated setting that meets the individual's needs and preferences. These PASRR protections align with state obligations under the Americans with Disabilities Act (ADA) and the Supreme Court's decision in *Olmstead* to serve people in the most integrated setting appropriate. PASRR requires that individuals with mental illness, intellectual disability, or a related condition are not admitted to Medicaid-certified nursing facilities (NF) until a full assessment is made, community alternatives identified, and person-centered services are recommended to meet the individual's medical and PASRR disability-related needs. For NF residents, PASRR also requires Resident Reviews to identify service and support needs when there are significant changes in condition; such as to increase independence, and coordinate transition planning from nursing facilities back to the community.

In 2012, the PASRR Technical Assistance Center (PTAC) published the first PASRR National Report, focused on the PASRR Level II tools that states administer to individuals who have shown evidence in a preliminary screen (Level I) of having a mental illness (MI), an intellectual disability (ID), or a related condition (RC) as defined in PASRR regulations (42 CFR 438.100-138). The second National Report, published in 2013, showed a dramatic improvement in the comprehensiveness of most Level II tools.

In 2014, the report is turning attention from reviewing Level II tools to two activities:

1. Assessing the tools that states use for their preliminary Level I screens
2. Analyzing PASRR-related items in the Minimum Data Set (MDS), the federally mandated assessment administered to all residents of Medicare- and Medicaid-certified nursing homes, upon admission and at regular intervals thereafter.

Level I Screens

The PASRR regulations at 42 CFR 483.100-138 give no detailed guidance about the Level I process, except what it must accomplish —identify all individuals who *may* have a PASRR disability (section 483.128(a)). To develop a method for assessing Level I tools, we identified five fundamental design principles necessary to identify all individuals who may have PASRR disabilities; i.e., no false negatives:

1. Sensitivity: The Level I tool should be sensitive enough to identify all individuals who *might* have a PASRR disability. It should generate some false positives – identify individuals who are later found (at Level II) not to have a PASRR disability. A Level I that generates no false positives will not identify all individuals who do, in fact, have a PASRR disability.
2. Specificity: The Level I tool should be as specific as possible. It should screen out individuals who show no signs of having a PASRR disability. As such, it should keep the number of false positives relatively low – but not zero.
3. Usability: The tool should be easy to understand and use at the level of professional qualification the state requires.
4. Accuracy: The tool should be accurate. For example, criteria for PASRR disabilities should be correct – as with age for ID and RC.
5. Informativeness: To the extent practical, tools should capture information that would help inform the Level II evaluation (if one is necessary).

Guided by these design principles, and by the kinds of evidence required to initiate a Level II evaluation, we developed a set of 14 data elements. For a given state's tool, data elements were assessed as *comprehensive*, *partial*, or *absent*, depending on how well the tool captured the relevant information on the 14 data elements. States were then assigned overall comprehensiveness scores based on the percent of total data elements that were considered comprehensive.

Because the CFR gives little guidance about the contents of a Level I screen, comprehensiveness scores do not directly reflect compliance – or lack thereof. Instead, they indicate only the degree to which a state's Level I tool adheres to the five design principles we articulate above. Moreover, comprehensiveness scores alone cannot characterize the overall operation of a state's Level I system.

The major finding of this analysis is that the Level I tools in most states do not adhere to the design principles we describe above, and are likely under-identifying individuals. This finding is congruent with previous observations from OIG and others. In some cases, tools are overly restrictive about whether an individual might have a PASRR disability; in other cases, they do not provide enough triggers for generating a referral for Level II evaluation.

As Table 1 shows, the majority of States – 30, or 58.8 percent – fall in the bottom two quartiles. Only a small number of States – 6, or 11.7 percent – have Level I tools that are fully or mostly comprehensive.

Table 1: Number and Percent of States within each "Comprehensiveness Quartile"

Level of Comprehensiveness	# States	% States
76%-100%	6	11.7%
51%-75%	15	29.4%
26%-50%	27	52.9%
≤ 25%	3	5.9%

The pattern of findings, and state responses to our analysis, indicates the challenging balance required for effective Level I tools. Some states with missing or overly restrictive triggers thought that the Level II evaluation should address issues that require professional judgment --- correctly preventing Level I screeners from working beyond their qualifications, but missing the point that any individuals not triggered at Level I will never be presented to Level II. States with Level I tools that required too much judgment from the screener said they would otherwise miss individuals who need PASRR protection --- correctly attempting to identify all affected individuals, but introducing both false negatives and positives by exceeding the screener's capabilities.

Minimum Data Set (MDS)

Version 3.0 of MDS contains two questions about whether a nursing home resident has previously been identified by PASRR as having MI, ID, or RC. Question A1500 (introduced in October 2010) asks whether an individual has previously been identified by the state PASRR Level II process as having any PASRR disability, and A1510 (introduced in April 2012) asks which type of PASRR disability an individual has.

The percentage of nursing home residents that should have been identified as having a PASRR-relevant disability in items A1500 and A1510 can be approximated from MDS diagnostic data. Comparing the diagnostic data with the PASRR questions gives an indication of the extent to which nursing home residents with a PASRR-relevant disability are being accurately identified; a fundamental measure of state PASRR program effectiveness and nursing facility compliance in completing the MDS.

We compared responses from the two PASRR MDS questions to responses from other MDS items that ask about PASRR-related diagnoses (note that MDS does not distinguish between ID and RC, and refers to both as ID/DD):

- *Mental illness*
  - Items I5700-I6100: anxiety disorder, depression, bipolar disorder, psychotic disorder, schizophrenia, post-traumatic stress disorder
  - Item I8000: "additional active diagnoses," indicated with ICD-9 codes(295 to 302 and 306 to 314
- *Intellectual disability/related condition –*
  - Item A1550: Down syndrome, autism, epilepsy, "other organic condition related to ID/DD)", "ID/DD with no organic condition"
  - Item I800: "additional active diagnoses," indicated with ICD-9 codes 317-319, 758, and V79

Our major finding is that PASRR systems are not accurately detecting all individuals who are otherwise diagnosed with MI. Tables 2 and 3 present the count of individuals who were in nursing homes on December 31, 2012 and December 31, 2013 ("census" figures); the national numbers for PASRR-related disabilities as recorded in the PASRR-related items listed above; and the national numbers for similar conditions. Because Question A1510 was not introduced until 2012, we present data only for 2012 and 2013.

As Table 2 shows, the number of individuals identified by PASRR as having ID or RC is about two thirds of the number of individuals recorded as having those conditions elsewhere in MDS. More study is required to understand to what extent the difference is a discrepancy or actual differences in the population.

Table 2: Rates of ID and Related Conditions in Nursing Homes (Year-End Census)

Year	**Total Number of Nursing Home Residents** (Census)	**Residents identified by Level II PASRR** (A1510B/C)	**Additional residents identified by ID/DD question** (A1510B/C *or* at least one A1550 condition)	**Additional residents identified by ICD codes** (A1510B/C *or* at least one A1550 condition *or* at least one I8000 code
2012	1,112,692	2.1% (22,917)	2.3% (25,540)	3.1% (34,061)
2013	1,292,583	2.2% (28,049)	2.4% (31,095)	3.2% (41,617)

Table 3 shows quite a different pattern for individuals with a mental illness: The number of individuals with MI recorded in the non-PASRR items was almost *20 times greater* than the number identified with serious MI in the PASRR items. Some of the larger number is due to less serious MI not meeting the PASRR definition. However, previous research shows that the prevalence of serious MI (relevant to the PASRR definition) in nursing home residents ranges from 7 percent[1] to 27 percent[2], – still well above what is recorded in MDS PASRR items. (To take into account differing definitions of serious MI, tables 10 and 11 show analysis using an additional, narrower definition of serious MI.)

Table 3: Rates of Mental Illness in Nursing Homes (Year-End Census)

Year	**Total Number of Nursing Home Residents** (Census)	**Residents identified by Level II PASRR** (A1510A)	**Additional residents identified by MI questions** (A1510A *or* at least one I5700-I6100 condition)	**Additional residents identified by ICD codes** (A1510A *or* at least one I5700-I6100 condition *or* at least one I8000 code
2012	1,112,692	3.6% (39,516)	59.4% (661,241)	69.4% (771,731)
2013	1,292,583	4.1% (52,460)	60.2% (778,126)	69.0% (892,272)

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[1] Bagchi, A., Verdier, J., Simon, S. (2009). How many nursing home residents live with a mental illness? *Psychiatric Services, 60*(70), pp. 958-964.

[2] Grabowski, D., Aschbrenner, K., Feng, Z., and Mor, V. (2009). Mental illness in nursing homes: Variation across states. *Health Affairs*, *28*(3), pp. 689-700.

There are at least two general explanations for this striking difference:

1. Nursing home assessors are accurately recording the PASRR status of residents, but state PASRR programs are failing to identify individuals with serious mental illness. PASRR programs could fail for a variety of reasons, including (but not limited to) poor or overly restrictive Level I screens, poor training of Level II evaluators, or overuse of the 30-day hospital discharge exemption and categorical determinations.
2. Nursing home assessors are not accurately recording PASRR status in MDS.

These explanations are not mutually exclusive.

Whatever the sources(s) of this difference, many individuals with MI are not being considered for community alternatives, and are not receiving the Specialized Services they need to preserve and improve their functioning so they can transition successfully back into the community.

Next Steps

CMS and PTAC will use the results of this evaluation to stimulate a discussion with states about the characteristics of a high-performing Level I system, which includes the tool and any policies and procedures associated with the tool, such as training for Level I assessors and quality monitoring of Level I assessments. We will consolidate what we learn from that discussion and provide technical assistance in a variety of ways to help states improve their Level I systems. We will also update this evaluation periodically, to track changes and trends over time.

PTAC will perform additional analyses using MDS and other data sources to understand the source of differences in the results presented here, and estimate more definitively how many individuals *should* have been identified by PASRR as having a relevant disability (for example, by looking at ADLs, IADLs, medications, and other information). Our technical assistance will include development of training materials to improve PASRR identification of individuals with MI in MDS, including webinars and issue papers.

1 Introduction

In 1999, the United States Supreme Court issued a landmark decision with profound consequences for the way states provide long-term services and supports (LTSS) to individuals with disabilities. In *Olmstead v. L.C.*, the Court found that the provisions of the 1990 Americans with Disabilities Act (ADA) applied not only to individuals with physical disabilities, but also to individuals with mental disabilities. Just as crucially, the Court declared that individuals with disabilities should be served in the most integrated, least restrictive possible setting. Because many individuals with disabilities receive long term services and supports (LTSS) from Medicaid, the burden of meeting the Court's mandate has fallen largely to states, which operate their Medicaid programs in partnership with the Federal government.

In the wake of the Court's decision, Congress authorized several new authorities in Medicaid law for providing community-based LTSS, along with several large grant programs. One of these programs, Money Follows the Person (MFP, first authorized in 2005), focused on transitioning individuals out of nursing facilities (NFs) and back into the community. None of these post-*Olmstead* laws or grant programs required states to *divert* individuals from NF admission – to help them remain in the community and avoid institutional placement altogether. Until recently, little attention was paid to a pre-*Olmstead* law that has been part of Title XIX of the Social Security Act since 1987: Preadmission Screening and Resident Review (PASRR). Created as part of the Nursing Home Reform Act, PASRR has important and unique powers in Medicaid law. It requires states to: 1) identify individuals who might be admitted to a nursing facility who have a serious mental illness (MI), or an intellectual disability (ID) or related condition (RC); 2) consider community placement first, and nursing facility only if appropriate; and 3) identify the PASRR-specific needs that must be met for individuals to thrive, whether in a NF or in the community. States cannot adequately meet their Olmstead objectives without leveraging the powers of PASRR.

The regulations that govern PASRR (42 CFR 483.100-138) require that states administer a PASRR program that has two steps. First, all individuals who apply for admission to Medicaid-certified NFs must be screened for the possibility that they have a PASRR disability. The Code of Federal Regulations (CFR) calls this a Level I screen. Individuals who "test positive" at Level I then receive a more in-depth evaluation to determine whether they have such a disability, and (if so) whether they need Specialized Services to address their PASRR-related needs. The CFR calls this a Level II evaluation. A positive Level II produces recommendations for the setting in which services should be received, and recommendations for Specialized Services, and these recommendations are intended to inform the individual's plan of care.

To help states conduct the necessary evaluations and determinations, the law allows states to claim an enhanced Federal match of 75 percent on all activities related to the administration of PASRR. PASRR is not classified as a service, but rather as a special kind of administrative activity, and it is a mandatory part of the basic Medicaid state Plan.

Because the basic functions of Medicaid state Plans do not typically come up for regular CMS review (unlike, for example, §1915(c) waivers for home and community-based services, or a targeted §1915(i) State Plan Benefit), evaluation of PASRR programs has often been overlooked by both state and Federal entities. The design and implementation of PASRR can thus drift away from requirements and good practice and become ineffective.

While CMS has long been committed to helping states improve their PASRR programs, it has not until recently had the ability to provide technical assistance or to conduct an empirical analysis of PASRR design and implementation. In 2009, prompted in part by a series of reports on PASRR from the Office of the Inspector General (OIG) and the Substance Abuse and Mental Health Services Administration (SAMHSA), the Centers for Medicare and Medicaid Services (CMS) returned focus to PASRR and funded the creation of the PASRR Technical Assistance Center (PTAC). A central aim of PTAC is to help states improve their PASRR programs, not only to bring them into compliance with Federal regulations, but also to integrate those programs with broader *Olmstead* efforts.

In 2012, PTAC released the first-ever national review of state PASRR programs. The first edition of the PASRR National Report assessed the compliance of Level II tools with Federal regulations and with a small number of good, modern clinical practices. The next National Report, released in 2013, showed marked improvement in the degree to which Level II's captured the data elements laid out in the 2012 report.

In the 2014 National Report, we turn our attention to two activities:

1. Analyzing the tools states use for their preliminary Level I screens.
2. Analyzing PASRR-related items in the Minimum Data Set (MDS), the federally mandated assessment administered to all residents of Medicare- and Medicaid-certified nursing homes, both shortly after admission and at regular intervals thereafter.

The analyses we present in this report describe the characteristics of PASRR Level I tools and the PASRR-related characteristics NF residents. Our aim is not to judge the literal compliance of state PASRR programs to federal requirements. We would need more information than the Level I forms or tools to do that. Our aim instead is to illuminate effectiveness, measured against the outcomes required by the federal rules, and to supply information that states can use to improve their systems.

Our analyses cannot provide direct information about the *implementation* of a state's PASRR program. A state could have an excellent Level I tool, but have an overall process that fails to identify individuals who have a PASRR disability – for example, if screeners do not use the tool correctly or if the state uses a poor algorithm for deciding when an individual requires a Level II. Conversely, a state could have a Level I tool that collects very little information, yet still have an overall process that works well – for example, if Level I screeners have the right kind of training and can exercise sound clinical judgment. Similarly, analyses of MDS can tell us about the characteristics of individuals in nursing homes and about the similarities and differences between PASRR-identified residents and other residents, and comparisons across states. But an analysis of MDS cannot directly tell us how those residents were evaluated, or whether the screening and evaluation they received was appropriate and properly performed.

The remainder of this report is organized as follows. Section 2 articulates a set of five design principles for Level I – sensitivity, specificity, usability, accuracy, and informativeness. It also details the data elements we have derived from those principles, and presents our findings. The key finding of this section is that Level I tools often do not reflect these design principles. Section 3 briefly reviews the relevant data collected in MDS, describes our methods for analyzing those data, and presents our findings. The key finding of this section is that the number of individuals who have been diagnosed with some form of MI far exceeds the number of residents who have been identified by

PASRR as having MI. This suggests that PASRR programs may produce a high number of false negatives, meaning they fail to identify many nursing home residents who have MI. As a result, some individuals are not receiving the Specialized Services they need to preserve and improve their functioning and become better candidates for transition back to the community. Section 4 considers that these findings may be related: Level I tools are sometimes too restrictive or lack the triggers necessary to initiate a Level II, thus preventing some individuals from receiving necessary Level II evaluations. Section 4 also sketches the next steps for PTAC and CMS, both to help states act upon these findings, and to conduct additional research.

We hope the 2014 National Report will stimulate productive conversations between (and among) states, CMS, and PTAC about how states can improve their Level I screening tools; about how Level I screening programs fits into PASRR programs as a whole; and about how about MDS can be used to make PASRR more robust and effective for the individuals it is intended to help.

2 Level I Screens

The PASRR regulations at 42 CFR 483.100-138 give no detailed guidance about the Level I process, except that it should identify all individuals who are "suspected of having" a PASRR-relevant disability (section 483.128(a)). To develop a Level I review instrument, we followed five fundamental principles about the design of Level I tools:

1. Sensitivity: The Level I should be sensitive enough to identify all individuals who *might* have a PASRR disability. As such, it should generate some false positives – it should sometimes identify individuals who are later found (at Level II) not to have a PASRR disability. A Level I that generates no false positives will "miss" some individuals who do, in fact, have a PASRR disability.
2. Specificity: The Level I tool should be as specific as possible. It should screen out individuals who show no signs of having a PASRR disability. As such, it should keep the number of false positives relatively low – but not zero.
3. Usability: The tool should be easy to understand and use at the level of professional qualification the state requires. In most states, there are very few qualifications. The logic of the questions should be straightforward, not relying too much on separate instructions or training. Again, commensurate with who does the screening --- typically hospital staff or even NF staff --- and the level of influence the state PASARR agencies have over these screeners. Each question should ask for one and only one answer. Screeners in most states must be able to complete the tool without the expert judgment that comes with years of clinical training and practice.
4. Accuracy: The tool should be accurate. For example, where the tool includes criteria for PASRR disabilities, those criteria should be correct – as with age for ID and RC.
5. Informativeness: To the extent practical, tools should capture information that would help inform the Level II evaluation (if one is necessary).

Guided by these design principles, we developed a set of 14 data elements for scoring Level I tools. Table 4 presents those data elements along with the keywords that guided our review of Level I tools. (More information about how we applied these keywords can be found in Section 2.1, Methods.)

In developing these data elements, we were informed by the Level II requirements in the CFR, but we did not replicate those requirements. Indeed, a Level I that replicates the requirements of a Level II is not a *preliminary* screen at all, and would generate false negatives – it would fail to identify individuals who in fact have a PASRR disability. Nonetheless, the criteria in the CFR for data required in the Level II can supply guidance about who is expected to be evaluated by Level II, and therefore the *kinds* of evidence Level I screeners should look for in order to identify those people. When these data elements are present, they can serve as triggers for a possible Level II evaluation, or for additional review when experienced clinicians are used to approve Level I screens (before a Level II evaluation) – what is sometimes informally called a Level 1.5.

It is worth noting that data elements 4.1 and 4.2 reflect the design principle of informativeness. According to the CFR, PASRR can sometimes be halted when it is determined that the individual does not have MI for PASRR purposes because dementia is also present – but this decision must be made at Level II, not Level I. The Level II can be terminated if a qualified professional determines that the individual has MI and a primary diagnosis of dementia (section 483.128(m)) that has advanced to be more prominent in the individual's experience than the MI. States can also apply a categorical determination for individuals with MI/ID/RC who by situation obviously need NF but would not benefit from Specialized Services (section 483.130(h)) – and categorical determinations involve abbreviated Level II evaluations. Even though categorical determinations are Level II functions, states may permit Level I screeners to apply the categories when documented evidence is available and no clinical judgment is required, or to collect this information to help inform the work of Level II evaluators or, if applicable, the "Level 1.5" approvers of the Level I.

One might imagine that a tool with all of the triggers in Table 5 would lead to a large number of false positives and, thus, an unnecessary number of Level II's – so many, in fact, that a state's Level II systems might be overwhelmed. This is a reasonable concern. However – as we will see in Section 3 – our analysis of MDS suggests that current PASRR systems generate too many false *negatives*, at least for MI. As recorded in MDS, PASRR identifies relatively few individuals who otherwise carry a diagnosis of at least one mental illness. We can therefore plausibly argue that Level I tools should be more "open-minded" about who should receive a Level II evaluation.

An additional element we did not examine is congruence of each state's Level I form with any categorical determinations the state uses, and whether those categories are approved in the Medicaid state plan. If Level I screeners are to apply categories, or give the information to those who do approve categorical determinations, then the Level I form must contain data elements sufficient to make and document those Level II decisions. Since an abbreviated Level II evaluation report is required for categorical determinations, (section 483.128(j)), the Level I tool, or a supplement to it, must collect all the information needed for that report.

Finally, it is important to again note that we have deliberately confined our analysis to the forms and tools states use. We have not yet assessed the policies and procedures states use to administer those tools – for example, the trainings that screeners receive, or the algorithms that state use to translate responses into a probability that a Level II is warranted. The influence of these policies and procedures on the success of Level I screens remains, for now, unmeasured.

Table 4: Data Elements for Level I Screen

Item #	Data Element	Keywords/Phrases
Mental Illness		
1.1	Mental illness diagnosis	diagnosis; serious mental illness; mental disorder
1.2	Substance abuse disorder	substance use
1.3	Interpersonal symptoms	interpersonal; serious difficulty interacting with others; altercations, evictions, unstable employment, frequently isolated, avoids others
1.4	Completing tasks	serious difficulty completing tasks, required assistance with tasks, errors with tasks; concentration; persistence; pace
1.5	Adapting to change	self-injurious, self-mutilation, suicidal, physical violence or threats, appetite disturbance, hallucinations, delusions, serious loss of interest, tearfulness, irritability, withdrawal
Intellectual/Developmental Disability or Related Condition		
2.1	ID/DD diagnosis	diagnosis; intellectual disability; developmental disability; mental retardation
2.2	ID/DD age of onset	age 18 (age of onset); evidence
2.3	Related condition diagnosis	evidence, history, diagnosis; affects intellectual functioning, affects adaptive functioning; autism, epilepsy, blindness, cerebral palsy, closed head injury, deaf
2.4	Related condition age of onset	age of onset; evidence; history; age 22
2.5	Receipt of services	agency serving individuals with ID/DD; past and present; services; services received; referred/referrals
Key Symptoms or Behavioral Indicators		
3.1	Undiagnosed condition	evidence; presenting evidence; suspected diagnosis; undiagnosed; indications
3.2	Functional limitations	mobility, self-care, self-direction, learning, understanding/use of language, capacity for living independently
Co-morbid Dementia		
4.1	Primary dementia diagnosis	dementia; primary diagnosis
4.2	Documented evidence of primary dementia	dementia work up; comprehensive mental status exam; primary diagnosis; evidence

2.1 Methods

Verifying the Contents of PTAC's Library of Level I Tools: Our library of Level I tools was first assembled in late 2009, from documents that staff in each of the 10 CMS Regional Offices had on file for the states in their Regions. To ensure that we reviewed the most current Level I tools, in February 2014 we sent state-by-state emails to the PASRR leads in the three key agencies of all 50 states and the District of Columbia: the Medicaid agency, the state mental health authority, and the state intellectual disabilities authority. (With the help of CMS Regional Office staff, we maintain an updated list of these contacts. We urge states to keep this information current.) These emails included:

- A brief description of our Level I review project;
- The name(s) of the state's Level I tools in our library; and
- Copies of the state's tools, attached to the email in their original formats.

We gave the PASRR staff in each state opportunity to verify whether the tools we had on file were the most current versions, and – if applicable – opportunity to send us the most up to date versions for the analysis.

Roughly six weeks later, we sent a reminder notice to each state that did not respond to the first email. Roughly one month after that, we sent a third and final notice to each state that had not yet responded. We asked these remaining states to respond within two weeks; otherwise, we would consider the tools we had on file to be the most current. All but two states responded to our notifications; but in both of these cases, the states acknowledged receiving the Fact Sheets that followed (see below for more). CMS made some additional follow-up by phone to ensure that no state would be surprised by this report.

Coding the tools: Each data element was given one of three scores:

- *Comprehensive*: The tool captured the data element thoroughly.
- *Partial*: The tool captured the data element partly but incompletely, or it misstated one or more criteria (including age).
- *Absent*: The tool did not capture this data element at all.

Data elements were coded as "partial" for a variety of reasons; some of the most common reasons are listed in Table 5. (For some data elements, no single reason predominated; we have labeled these cases "Various.") Early testing of the review instrument showed a high degree of reliability across coders.

Table 5: Common Reasons for Scores of "Partial" on Each Data Element

Data Element	Common Reasons for "Partial"
1.1	None (no partials)
1.2	None (no partials)
1.3	Time limit placed on symptoms (e.g., last 6 months)
1.4	Time limit
1.5	Time limit
2.1	Diagnosis of ID and RC asked in the same question (should be separately)
2.2	ID age of onset stated incorrectly (should be 18)
2.3	Diagnosis of ID and RC asked in the same question
2.4	RC age of onset state incorrectly (should be 22)
2.5	Time limit placed on referrals or receipt of services
3.1	Various
3.2	Various
4.1	Tool indicates that evidence of dementia halts PASRR (i.e., no Level II)
4.2	Various

For each state, we calculated an overall "comprehensiveness score" – the total number of data elements scored as comprehensive, divided by the total number of data elements (out of 14 altogether), taken as a percentage. Note that the distinction between "absent" and "partial" does not affect the final score – only the number of elements scored as "comprehensive" figures into this value.

Because the CFR gives little guidance about the contents of a Level I screen, comprehensiveness scores do not directly reflect compliance – or lack thereof. Instead, they indicate only the degree to which a state's Level I tool adheres to the five design principles we articulate above. Moreover, comprehensiveness scores do not capture any information about the overall operation of a state's Level I system.

Verifying the accuracy of our reviews: Once coders completed their review of all 51 Level I tools, we drafted individualized "Fact Sheets" for each state. Each Fact Sheet:

- Described the nature of PTAC's review project;
- Listed the 14 data elements and the state's score on each element;
- Presented a set of suggestions for revising the state’s current tool; and
- Listed the names of the tools we reviewed (to verify, one last time, that we had reviewed the state's most current tool).

The fact sheets are only given to each state for self-assessment purposes, they are not available to others. We gave staff in each state two weeks to respond with optional comments on its Fact Sheet or to supply the correct version of the Level I tool. In a small number of cases, we found we had reviewed the incorrect tool; in those cases, we conducted another review and gave the state time to comment on their draft Fact Sheet. PTAC received electronic responses from a total of 47 states and the District of Columbia. The remaining four states were contacted by phone, confirming that they had received their Fact Sheets.

2.2 Findings and Discussion

The major finding of this study is that the Level I tools in most states do not reflect the design principles we identified above. In some cases, tools were too restrictive about whether an individual might have a PASRR disability; in other cases, tools did not include some important pieces of evidence that would trigger a Level II evaluation. As Table 6 shows, the majority of states – 30, or 58.8 percent – fall in the bottom two quartiles. Only a small number of states – 6, or 11.7 percent – have Level I tools that are fully or mostly comprehensive. Table 7 lists all 51 States and the quartiles in which they scored. (This table is included in the Executive Summary as Table 1.)

Table 6: Number and Percent of States within each "Comprehensiveness Quartile"

Level of Comprehensiveness	# States	% States
76%-100%	6	11.7%
51%-75%	15	29.4%
26%-50%	27	52.9%
≤ 25%	3	5.9%

The pattern of findings and state responses to the findings indicates the challenging balance required for effective Level I tools. In most states Level I screeners are not qualified to make judgments about mental illness or intellectual disability (in some states are non-professionals); but the tool they use must have triggers to identify everyone who should be evaluated by qualified Level II evaluators. Some states with missing or overly restrictive triggers thought that only the Level II evaluation should collect information on any issues that require professional judgment --- correctly preventing Level I screeners from working beyond their qualifications, but missing the point that individuals not triggered at Level I will never be presented to Level II. States with Level I tools that required too much judgment or require the screener to make Level II decisions, said they would otherwise miss individuals who need PASRR protection --- correctly attempting to identify all affected individuals, but introducing both false negatives and false positives by exceeding the screener's capabilities.

It is not yet clear exactly what the effects may be on PASRR programs from this mismatch between the design principles we have identified and the tools states use. However, previous studies of PASRR, and impressions from most experts in the field, have long indicated that Level I is missing many individuals it should be identifying. Our analysis of MDS, presented next in Section 3, suggests that inadequacy of Level I tools are causing PASRR programs to be too conservative in identifying individuals who have serious MI.

Table 7: States by "Comprehensiveness Quartile" of Level I tools

76%-100% (6)	**51%-76% (15)**	**26%-50% (27)**	**0%-25% (3)**
Connecticut	Alaska	Alabama	Oklahoma
Iowa	Arkansas	Arizona	Oregon
Maine	California	Colorado	Texas
Nebraska	Florida	Delaware	
Nevada	Idaho	Dist. of Columbia	
South Dakota	Kansas	Georgia	
	Maryland	Hawaii	
	Mississippi	Illinois	
	New Jersey	Indiana	
	North Carolina	Kentucky	
	North Dakota	Louisiana	
	Pennsylvania	Massachusetts	
	Rhode Island	Michigan	
	South Carolina	Minnesota	
	West Virginia	Missouri	
		Montana	
		New Hampshire	
		New Mexico	
		New York	
		Ohio	
		Tennessee	
		Utah	
		Vermont	
		Virginia	
		Washington	
		Wisconsin	
		Wyoming	

3 The Minimum Data Set (MDS)

All residents of Medicaid- and Medicare-certified certified nursing homes are assessed using a standardized Resident Assessment Instrument called the Minimum Data Set (MDS). MDS collects many details about an individual's medical, social, and functional status, including active diagnoses, cognitive status, and ability to perform activities of daily living (ADLs) such as bathing and dressing. MDS version 3.0 also contains two questions about whether an individual has been identified by the state's PASRR process as having a serious MI, ID, or RC. Question A1500 (introduced in October 2010) asks whether an individual has been identified as having a PASRR disability, and A1510 (introduced in February 2012) asks which type of PASRR disability an individual has. The introduction of these items enables us to ask important questions about the characteristics of nursing home residents. Using MDS data for 2011-2013 (the last three full years of MDS 3.0), we focus on the following two questions:

1. Of the individuals admitted to nursing homes, what percentage has been identified as having a PASRR disability?
2. How accurately do state PASRR systems identify individuals who have PASRR-related diagnoses as recorded elsewhere in MDS?

The extent to nursing homes accurately complete MDS is a fundamental measure of the effectiveness of a state's PASRR programs.

3.1 Methods

Our dataset covers the period between the introduction of MDS 3.0 on October 1, 2010 and December 31, 2013. In general our method was to compare responses to PASRR MDS questions to responses to other items in MDS that ask about diagnoses related to PASRR. For each analysis, we construct a numerator and a denominator.

The denominator represents the total NF population. In order to capture both short and long term stays, we construct the denominator in two ways:

- *New Admissions:* This method captures mostly shorter term stays. MDS 3.0 includes data for NF admissions, assessments, and discharges from late 2010 through the end of 2013. We select the first admission assessment for residents who have no admission record in prior years. If there is more than one admission record in a given year, we select the first one. Residents with long stays, admitted before MDS 3.0 are not included in this count. The new admissions method is the one most commonly reported in the academic literature (e.g., Grabowski et al., 2009). At this point in our analysis, looking back only to 2010, we do not find the results very clear, and include them in this report to augment the census data method results.

- *Year-End Census:* For our second methodology, we include only residents in NFs on December 31, 2012 and 2013 – a census method. This method captures mostly long term residents. We create a census on this date using a method that mirrors the one CMS has used to define active residents. An active resident is defined as having a "target date" (assessment date) less than 150 days prior to December 31 and no discharge record between this assessment and December 31. For active residents, we then select the most recent annual or admission record, because the PASRR items are not recorded on quarterly assessments. The census method is the one that CMS uses to generate the MDS tables it provides online; it is also the method used by the Long-Term Care Statistics Branch at the National Center for Health Statistics (e.g., NCHS, 2013). This method is used for the tables in the Executive Summary.

We find that the two methods have a small overlap — less than 20% of residents are counted in both denominators. Since the pattern of rates (as opposed to counts) is similar for both denominators, the differences are not important for this report. We will look at these issues more closely in later analysis, and invite comment.

For both methods, we include only records from facilities identified as Medicaid-certified NFs, since all individuals who apply for admission to NFs must first be screened by Level I PASRR. (Many of these facilities are dually certified as Medicaid NFs and Medicare skilled nursing facilities (SNFs). However, the Medicare certification status does not impact our inclusion criteria.) Because related conditions have no established diagnostic value outside PASRR, we treat individuals with ID and individuals with RC as belonging to the same category.

The numerator varies by item. For ID/RC, we construct the numerator in two ways:

1. We take the number of individuals for whom Question A1510B *or* A1510C is checked, indicating ID or RC for the purposes of PASRR.

2. To the number of individuals computed in (1), we add the number for whom A1550 contains one or more of the answers: Down syndrome, autism, epilepsy, "other organic condition related to ID/DD," "ID/DD with no organic condition." This method reveals the additional information we gain by looking at diagnostic information in items other than the PASRR questions A1510B and A1510C.

To compute the share of individuals who have MI, we construct the numerator in four ways, taking into account different definitions of MI.

1. We take the number of individuals for whom Question A1510A is checked, indicating MI for the purposes of PASRR.
2. To the number of individuals computed in (1), we add the number who have at least one MI diagnosis as recorded in Section I: anxiety disorder (I5700), depression (I5800), manic depression (bipolar disease, I5900), psychotic disorder (I5950), schizophrenia (I6000), and post-traumatic stress disorder (PTSD, I6100). Following Grabowski et al. (2009), we calculate the numerator in two ways:
    a. *Broad*: We include individuals with all of the diagnoses listed above
    b. *Narrow*: We include only individuals with schizophrenia and manic depression (bipolar disorder) – the two psychiatric conditions most often associated with institutionalization
3. To the number of individuals computed in (2), we add the number who have at least one ICD-9 code indicating a PASRR disability – codes 295 to 302, and codes 306 to 314.

Note that the methods (2.) and (3.) reveal the additional information we gain by looking at diagnostic information in items other than the PASRR question A1510A.

Percentages are calculated as $\frac{Numerator}{Denominator} \times 100$.

3.2 Findings and Discussion

Tables 8 through 11 present the national figures for nursing homes in 2012 and 2013; for specific types of PASRR disabilities; and for similar conditions as recorded in MDS diagnostic questions, listed above. Tables 8 and 9 are for ID and related conditions, presented first by new admissions (capturing shorter stay residents) and then by the census method (a point in time measure capturing longer stays). Tables 10 and 11 for MI are presented in the same manner. (Table 9 also appears in the Executive Summary as table 2. Table 11 expands on Table 3 in the Executive summary, adding the narrow definition of MI.)

Tables 8 and 9 show that in 2012 and 2013 the number of individuals identified by PASRR as having ID and related conditions (ID/DD in MDS) roughly corresponds to the number of individuals recorded elsewhere in MDS as having those conditions. Among these individuals, PASRR appears to be working relatively well – it correctly identifies about two thirds of the individuals it potentially should identify. The results are congruent for both the new admissions and the facility census methods. The former probably shows overall lower rates of ID/DD because over a year there are a higher proportion of short-term rehabilitation residents without ID/DD. See discussion of the two denominators in section 3.1, Methods.

Table 8: Rates of ID and Related Conditions in Nursing Homes (New Admissions)

Year	**Total Number of Nursing Home Residents** (New Admissions)	**Residents identified by Level II PASRR** (A1510B/C)	**Additional residents identified by ID/DD question** (A1510B/C *or* at least one A1550 condition)	**Additional residents identified by ICD codes** (A1510B/C *or* at least one A1550 condition *or* at least one I8000 code
2012	1,598,558	0.7% (10,825)	1.2% (19,321)	1.3% (21,471)
2013	1,486,812	0.9% (13,092)	1.3% (18,819)	1.4% (21,097)

Table 9: Rates of ID and Related Conditions in Nursing Homes (Year-End Census)

Year	**Total Number of Nursing Home Residents** (Census)	**Residents identified by Level II PASRR** (A1510B/C)	**Additional residents identified by ID/DD question** (A1510B/C *or* at least one A1550 condition)	**Additional residents identified by ICD codes** (A1510B/C *or* at least one A1550 condition *or* at least one I8000 code
2012	1,112,692	2.1% (22,917)	2.3% (25,540)	3.1% (34,061)
2013	1,292,583	2.2% (28,049)	2.4% (31,095)	3.2% (41,617)

Tables 10 and 11 show that the pattern for individuals with MI is quite different. Each table show results for both broad and narrow definitions of MI, as described above in Methods. Table 10 displays results using the new admissions method of counting residents; Table 11 displays results using the year-end census method.

Table 10: Rates of MI in Nursing Homes, Defined Broadly and Narrowly (New Admissions)

			Broad Definition	**Broad Definition**	**Narrow Definition**	**Narrow Definition**
Year	**Total Nursing Home Residents** (New Admissions)	**Residents identified by Level II PASRR** A1510A	**Additional residents identified by MI questions** A1510A *or* at least one I5700-I6100 condition	**Additional residents identified by ICD codes** A1510A *or* at least one I5700-I6100 condition *or* at least one I8000 code	**Additional residents identified by MI questions** A1510A *or* at least one I5700-I6100 condition	**Additional residents identified by ICD codes** A1510A *or* at least one I5700-I6100 condition *or* at least one I8000 code
2012	1,598,558	1.1% (18,320)	39.6% (633,219)	49.9% (797,927)	4.5% (71,978)	19.1% (304,794)
2013	1,486,812	1.6% (23,296)	39.3% (584,497)	48.6% (722,615)	4.7% (69,340)	17.5% (260,182)

Table 11: Rates of MI in Nursing Homes, Defined Broadly and Narrowly (Year-End Census)

			Broad Definition	**Broad Definition**	**Narrow Definition**	**Narrow Definition**
Year	**Total Nursing Home Residents** (Census)	**Residents identified by Level II PASRR** A1510A	**Additional residents identified by MI questions** A1510A *or* at least one I5700-I6100 condition	**Additional residents identified by ICD codes** A1510A *or* at least one I5700-I6100 condition *or* at least one I8000 code	**Additional residents identified by MI questions** A1510A *or* at least one I5700-I6100 condition	**Additional residents identified by ICD codes** A1510A *or* at least one I5700-I6100 condition *or* at least one I8000 code
2012	1,112,692	3.6% (39,516)	59.4% (661,241)	69.4% (771,731)	11.0% (122,798)	31% (345,110)
2013	1,292,583	4.1% (52,460)	60.2% (778,126)	69.0% (892,272)	11.9% (153,513)	29.6% (382,280)

New admissions method(Table 10): Using a denominator that captures shorter stay residents, under the narrow definition of MI, the number of individuals recorded in MDS diagnostic fields as having MI in 2012 and 2013 was three to ten times greater than the number of individuals recorded as having MI in question A1510A. Under the broad definition of MI, the number of individuals recorded in MDS diagnostic fields as having MI in 2012 and 2013 was 25 to 30 times greater than the number of individuals recorded as having MI in question A1510A.

Year-end census method (Table 11):Using a denominator that captures long stay residents, under the narrow definition of MI, the number of individuals recorded in MDS diagnostic fields as having MI in 2012 and 2013 was three to seven times greater than the number of individuals recorded as having MI in question A1510A. Under the broad definition of MI, the number of individuals recorded in MDS diagnostic fields as having MI in 2012 and 2013 was 15 to 17 times greater than the number of individuals recorded as having MI in question A1510A.

Tables 10 and 11 both reveal the same striking pattern: The number of people identified by PASRR as having MI is substantially smaller than the number of people who carry a diagnosis of MI as recorded elsewhere in the MDS. More people show a diagnosis of MI under the census method than under the new admissions method. This may be because the majority of new admissions are for short-stay residents who do not have any indications of serious MI and require NF care only for convalescence. The source of this difference is a subject for future analysis.

4 General Discussion and Next Steps

Our analysis of Level I tools across the country suggests that the tools in many states are too restrictive or lack the items necessary to trigger a Level II evaluation, and therefore may be failing to identify many people who have a PASRR disability. Our analysis of MDS data supports this idea. While PASRR correctly identifies individuals with ID and RC, PASRR fails to identify many individuals who have a recorded diagnosis of MI.

To be sure, some individuals with a diagnosis of MI may not have met the criteria for serious MI under PASRR, and would instead have been classified as having an isolated episodic mental illness. However, published prevalence estimates of serious mental illness in nursing home residents range from seven percent (Bagchi et al, 2009) to 27 percent (Grabowski et al., 2009), well above the roughly one to four percent recorded in MDS PASRR items. Therefore, it is highly unlikely that the difference between episodic MI and serious MI can account for a difference of this size.

There are at least two general explanations for this dramatic difference:

1. Nursing home assessors are accurately recording in MDS the residents who have been determined by the state to have PASRR Level II status, but state PASRR programs are failing to identify all of the individuals with serious mental illness. State PASRR programs could fail for a large number of reasons, including (but not limited to) poor or overly restrictive Level I screens, poor performance of Level II evaluators, or overuse of the 30-day hospital discharge exemption and categorical determinations.
2. Nursing home assessors are not accurately recording state PASRR status in MDS.

These explanations are not mutually exclusive.

Whatever the cause(s) of this difference, our findings indicate that many individuals with MI are not being assisted by PASRR --- they are not being considered for community alternatives; are not receiving the Specialized Services they need to preserve and improve their functioning while they are nursing home residents; and will be less likely to transition back into the community.

4.1 Next Steps: Level I

To leverage and extend the results of this analysis, CMS and PTAC will:

- Educate states about how to design a strong Level I tool, and about the essential role a Level I plays in the overall success of a state's PASRR program.
- Use the results of this evaluation to stimulate a discussion with states about the characteristics of a high-performing Level I system, which includes the tool and any policies and procedures associated with the tool, such as training for Level I assessors and quality monitoring of Level I assessments.
- Target technical assistance to states whose comprehensiveness scores fall in the bottom two quartiles.
- Update the results of this evaluation periodically, to track changes and trends over time.

4.2 Next Steps: MDS

To leverage and extend the results of this analysis, CMS and PTAC will:

- Communicate to state agencies and NFs their respective responsibilities under Federal requirements to accurately identify MI and record PASRR status.
- Provide individualized TA to help states identify the root causes of the low rates of PASRR identification in MDS.
- Develop training materials to improve PASRR identification of individuals with MI in MDS, including webinars and issue papers.
- Work with the association of resident assessment coordinators to ensure that nursing homes are completing MDS PASRR questions correctly.
- Perform additional analyses using MDS and published research to estimate more definitively how many individuals *should* have been identified by PASRR as having a relevant disability (for example, by looking at ADLs, IADLs, medications, and other information captured in MDS).
- Study MDS diagnostic items and their definitions to identify any needed improvements for consistent data.

5 About PTAC and Requesting Technical Assistance

PTAC has assembled a team of national experts on PASRR policy and implementation who regularly work directly with states and CMS. Any state agencies working with PASRR may ask a question or request assistance free of charge. PTAC reaches out particularly to the three agencies with statutory responsibility for PASRR: the Medicaid agency, the state mental health authority (SMHA), and the state intellectual disabilities authority (SIDA).

We urge these agencies to keep contact information up to date at www.PASRRassist.org, and with CMS regional offices, so that you will receive notice of monthly PASRR webinars, quarterly PARR calls with the states in your region, and communications such as this report. You will also receive information on special initiatives such as the work group for states wishing to modernize the way in which they pay for and provide the disability-specific supports known as Specialized Services.

Much of the information and training materials PTAC has assembled since 2009 is available on the Center's website: www.PASRRassist.org, and may be useful to others involved with long term care, rebalancing and *Olmstead* initiatives, and services for individuals with MI or ID.

PTAC's technical assistance to states:

- Is free;
- Is confidential (except in cases where the health and welfare of individuals may be jeopardized); and
- May include in-person visits (e.g., for strategic planning or to help develop interagency collaboration).

States may request technical assistance on any of the topics discussed in this report through the PTAC website (www.PASRRassist.org) or by contacting the Director of PTAC, Ed Kako, at ekako@mission-ag.com.

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