

2015 PASRR National Report

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



A joint partnership of Truven Health Analytics

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Executive Summary

This fourth Preadmission Screening and Resident Review (PASRR) National Report updates the findings of our 2014 National Report on nursing home data and state Level I preliminary screening tools. Nursing home data indicate that in most states PASRR under-identifies individuals with serious mental illness, and to a lesser extent, intellectual disability. These data corroborate our finding that in many states the Level I PASRR initial screening tools do not contain the necessary triggers to identify individuals who could have serious mental illness (SMI), intellectual disability (ID), or a related condition (RC), who should be fully evaluated by PASRR Level II. In subsequent discussion with states, and in close collaboration with our partners at CMS, the PASRR Technical Assistance Center (PTAC) team agreed with state concerns that we do not yet have enough evidence-based guidance about Level I tools for a final conclusion that those screens should contain all of the data elements in our analysis. However, it is difficult to imagine eliminating any one element from PASRR Level I without also missing some individuals, because each element identifies different populations or different needs. While many states have improved their tools since last year, or are working to do so, the need for system improvement nationally is still 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 SMI, ID, or RC 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 SMI, ID, or RC not be admitted to Medicaid-certified nursing facilities (NF) until a full assessment is made, community alternatives are 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 NFs back to the community.

In 2012, 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 SMI, ID, or 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, we turned our 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.

In this 2015 National Report, we update our findings in both areas – Level I screens and MDS.

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 articulated five fundamental design principles necessary to identify all individuals who may have PASRR disabilities – thereby producing 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 – it should 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 of onset for ID (by age 18) and RC (by age 22).

5. Informativeness: To the extent practical, tools should capture information that would help inform the Level II evaluation (if necessary, because Level I is positive).

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. Although we held these data elements constant, we frequently accepted information from state staff that their tools did indeed contain more of these elements than we initially gave those tools credit for.

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. 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. Instead, they indicate the degree to which a state's Level I tool adheres to the five design principles we articulate above, and the likelihood that the Level I tool will enable the state to comply with the requirement to identify the correct individuals. Moreover, comprehensiveness scores alone cannot characterize the overall operation of a state's Level I system.

The major finding of this analysis is that many states have used the feedback we provided last year to improve their Level I tools. Despite these improvements, the tools that states use do not always 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, and with the MDS analysis in the second part of this report. In some cases, tools are overly restrictive about whether an individual might have a PASRR disability, because they essentially replicate the requirements of a Level II; in other cases, they do not provide enough triggers for generating a referral for Level II evaluation, because they omit questions that can identify individuals with potential PASRR disabilities (e.g., by failing to ask about substance abuse).

As Table 1 shows, the majority of states – 33, or 64.7 percent – fall in the top two quartiles. A sizable share of states – 20, or 39.2% – fall in the uppermost quartile. Table 7 lists all 51 States and the quartiles in which they scored.

These findings represent a dramatic improvement over our 2014 analysis, when the majority of states – 58.8 percent – fell within the bottom two quartiles. Clearly many states

have used the feedback from the 2014 Report and modified their tools to adhere to the design principles it articulated.

Table 1: Number and Percentage of States within Each "Comprehensiveness Quartile" with 2014 Comparison Data

Level of Comprehensiveness	# States	% States 2015	% States 2014
76%-100%	20	39.2%	11.7%
51%-75%	13	25.5%	29.4%
26%-50%	16	31.4%	52.9%
≤ 25%	2	3.9%	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 positives and false negatives 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 SMI, 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 who 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).

SMI:

- Items I5700-I6100: bipolar disorder, psychotic disorder, schizophrenia
- Item I8000: "additional active diagnoses", indicated with relevant ICD-9 codes under 295 and 296

ID/RC:

- 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 this year reinforces last year’s finding: PASRR systems are not accurately detecting all individuals who are otherwise diagnosed with SMI. It should be noted, however, there has been insufficient time to see improvements due to the changes states have made to their Level I tools following the 2014 National Report. Tables 2 and 3 present the count of individuals who were in nursing homes on December 31, 2012; December 31, 2013; and December 31, 2014 ("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 -2014.

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 elsewhere in MDS as having those conditions.

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

Year	Number of Nursing Home Residents (Census)	A1510B/C (PASRR)	A1510B/C or At Least One A1550 (PASRR or Other Dx)	A1510B/C or At Least One A1550 or At Least One I8000 (ICD) (PASRR or Other Dx)
2012	1,112,560	2.1% (22,918)	2.3% (25,540)	3.1% (34,065)
2013	1,296,579	2.2% (28,454)	2.4% (31,502)	3.2% (42,015)
2014	1,288,598	2.2% (28,531)	2.5% (31,734)	3.3% (42,134)

Table 3 shows quite a different pattern for individuals with a mental illness: The number of individuals with SMI recorded in the non-PASRR items was 5 to 9 times greater than the number identified with serious SMI in the PASRR items.

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

Year	Number of Nursing Home Residents (Census)	A1510A (PASRR)	A1510A or At Least One I5700-I6100 (PASRR or Other Dx)	A1510A or At Least One I5700-I6100 or At Least One I8000 (ICD) (PASRR or Other Dx)
2012	1,112,560	3.6% (39,522)	19.4% (215,517)	36.4% (404,780)
2013	1,296,579	4.1% (53,016)	20.3% (263,561)	35.2% (456,625)
2014	1,288,598	4.4% (56,906)	20.2% (259,656)	32.9% (424,308)

Previous research has shown that the prevalence of SMI (relevant to the PASRR definition) in nursing home residents ranges from 7¹ percent to 27² percent – again, well above what is recorded in MDS PASRR items.

The extent of this difference indicates that there are some significant problems. There are at least two general explanations for this 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, failing to note individuals that do in fact have PASRR Level II evaluations. In other words, assessors are not completing the PASRR items in the MDS correctly.

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

These explanations are not mutually exclusive.

Whatever the source(s) of this difference, many individuals with SMI are not being identified, and therefore not benefiting from PASRR. The result is that between 375,000 and 400,000 thousand individuals with SMI are not considered for community alternatives by a PAS and therefore inappropriately institutionalized. For the individuals involved, this constitutes both a civil rights violation and a personal tragedy. Once admitted, such individuals are not receiving the Specialized Services they need to preserve and improve their functioning. Without Specialized Services or Level II Resident Review, individuals are very unlikely to transition successfully back into the community. PASRR is not merely an administrative step in the nursing home admission process – a series of boxes to be checked. On the contrary, PASRR affects lives.

Next Steps

CMS and PTAC will use the results of this evaluation to continue our 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 continue to 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 developing training materials to improve PASRR identification of individuals with SMI in MDS, including webinars and issue papers.

In addition, we will turn our attention to a new topic in the coming year: quality monitoring and quality improvement. We will look at the systems that states have in place to track quality-related data in their PASRR programs, and to use what they find to make their programs more robust and effective. We have not yet settled on the details of our quality analysis. Once we do, we will let states know what we intend to look at, and when the results of our next analysis will first be shared with states.

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 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 that are intended to inform the individual's plan of care.

To help them conduct the necessary screens, 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 option), 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 tools captured the data elements laid out in the 2012 report.

In the 2014 National Report, we turned 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 update our 2014 findings on the characteristics of PASRR Level I tools and the PASRR-related characteristics of NF residents, using data through the end of 2014. As in previous years, our aim is not to judge the literal compliance of state PASRR programs with 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 reiterates a set of five design principles for Level I that we first articulated in the 2014 National Report – 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 many states have improved the quality of their Level I tools, or are in the process of doing so. Even with these improvements, however, many Level I tools still do not reflect the design principles we have laid out. 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 remains unchanged from last year: 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 2015 National Report will help promote the productive conversations that have taken place over the last year 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 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 PASRR 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. These 14 elements represent “plausible triggers” – items that seem, logically, to predict the possible presence of MI, ID, or RC.

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 review and 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 Level II evaluations 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 care 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 4 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, 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.

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.

A final note about the data elements we used in our analysis. Following our 2014 analysis, some states questioned whether the data elements we had identified were strongly supported by evidence. This was especially true for two items:

1. The item about substance abuse. We included this data element because there is a high correlation between MI and substance abuse disorders.
2. Our claim that Level I's should not impose a strict "look-back period" to determine whether an episode of mental illness has previously impaired an individual's functioning. If the look-back period is too restrictive, we reasoned, PASRR may miss individuals who are at greater risk of psychiatric challenges when they enter the (sometimes stressful) environment of a nursing facility.

In further discussion with states, and in close collaboration with our partners at CMS, the PTAC team agreed with state concerns that we do not yet have evidence-based reasons for a final conclusion that Level I should include all of the data elements in our analysis. However, it is difficult to imagine eliminating any one element without also missing some individuals, because each element identifies different populations or different needs. Whether these items really do distinguish between people with a PASRR disability and people who lack such a disability is an empirical question. For example, while we

continue to find that it is too restrictive in Level I to limit the look-back period for episodes of mental illness to the same timeframe used in Level II, we do not set an alternative time frame, because we currently lack data about the most effective time frame. As states modify their Level I tools and begin using them in the field, we encourage state staff to analyze the data they get back to determine whether these items are truly discriminating. PTAC can help with designing these analyses.

In our conversations with states, we also have been made aware that they often define the age of onset for intellectual and developmental disabilities in ways that do not align with the PASRR rules. Most commonly, states set the upper age for both at 22 – usually the definition used in the states’ 1915(c) waiver programs for serving individuals with I/DD. The CFR, on the other hand, stipulates that the upper age for intellectual disabilities is 18. Our use of the CFR age boundary has created some confusion and consternation. In future analyses of Level I tools, we will accept as comprehensive any age boundary for I/DD that is *equal to or greater than* the age boundary set in the CFR. In other words, we will treat as comprehensive an item that stipulates that an intellectual disability must manifest by the age of 21 or 22. The only situation that would prompt us to mark that data element as partial or absent would be stipulating an age that is *below* the age set in the CFR (say, 12 or 15 – a situation that we believe is highly unlikely). It is the job of evaluators at Level II to determine whether an intellectual disability manifested by the age of 18, or a related condition by the age of 22. The Level I can be more open-minded about age. As we have said before, the Level I should generate some false positives, and this is a case in which false positives are acceptable.

One distinct advantage of retaining the same Level I data elements for the 2015 Report is that it allows us to compare directly between the findings of the last National Report and the findings of this one. We will therefore be able to quantify the degree to which states have incorporated these plausible data elements/triggers into their screens, or are working to do so.

Table 1: 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
2.4	Related condition age of onset	age of onset; evidence; history; age 22 head injury, deaf
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

Notifying States of Our Analysis and Giving Them the Option to Respond: On March 18, 2015, PTAC notified states it was preparing to review state Level I tools for the 2015 National Report. PTAC sent each state the latest Level I form on file and gave states an opportunity to respond with their most recently updated Level I form. States were given until March 27 to respond with an updated Level I tool. Twenty-three (23) states responded with an updated Level I form for PTAC's review, while the other 28 states indicated they were either in the process of updating their Level I form, or were using the same form from the 2014 review. PTAC reviewed the 28 updated Level I forms sent by states, and, on August 19, sent out draft, state-specific Fact Sheets to all 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.) States were given the option to respond to the draft Fact Sheets with any comments or concerns by August 28. Thirteen (13) states responded with questions or a new tool. PTAC reviewed the new tools and feedback, and sent newly revised Fact Sheets to 12 of the states.

The Fact Sheets are only given to each state for self-assessment purposes; they are not accessible to other states. Each Fact Sheet:

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

It is important to note that we accepted and reviewed updated Level I screens that were still in draft form, and not yet in use in the field. In this way, we gave states as much credit as possible for the improvements they had made.

Coding the tools: Each data element in each tool 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"; see Table 4 for a description of each element.) Early testing of the review instrument showed a high degree of reliability across coders.

Table 2: 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. Instead, they indicate the degree to which a state's Level I tool adheres to the five design principles we articulate above, and the likelihood that the Level I tool will enable the state to comply with the requirement to identify the correct individuals. Moreover, comprehensiveness scores do not capture any information about the overall operation of a state's Level I system.

2.2 Findings and Discussion

The major finding of this analysis is that many states have improved the quality of their Level I tools, but that many still 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 – 33, or 64.7 percent – fall in the top two quartiles. (This table is included in the Executive Summary as Table 1.) A sizable share of states – 20, or 39.2% – fall in the uppermost quartile. Table 7 lists all 51 States and the quartiles in which they scored. These findings represent a dramatic improvement over our 2014 analysis, when the majority of states – 58.8 percent – fell within the bottom two quartiles. Clearly many states have used the feedback from the 2014 Report and modified their tools to adhere to the design principles it articulated.

Table 3: Number and Percentage of States Within Each "Comprehensiveness Quartile," with 2014 Comparison Data

Level of Comprehensiveness	# States	% States 2015	% States 2014
76%-100%	20	39.2%	11.7%
51%-75%	13	25.5%	29.4%
26%-50%	16	31.4%	52.9%
≤ 25%	2	3.9%	5.9%

Despite the improvements we have seen over 2014, the need for national improvement is still evident, as 18 states – more than a third – fall within the bottom two quartiles. We have been talking to lower-scoring states about why their results appear as they do, and to provide support for any changes they wish to make to their Level I screens.

The pattern of findings and state responses to the findings indicate 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 they 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 require too much judgment or that 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.

The degree to which state PASRR programs might be affected by the mismatch between the design principles we have identified and the tools states use is unknown. 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 is causing PASRR programs to be too conservative in identifying individuals who have serious MI.

Table 4: States by "Comprehensiveness Quartiles" of Level I Tools

76%-100% (19)	51%-76% (14)	26%-50% (16)	0%-25% (2)
Alaska	Arkansas	Alabama	Oregon
Arizona	California	Colorado	Wyoming
Connecticut	Florida	Delaware	
District of Columbia	Maryland	Illinois	
Georgia	Michigan	Indiana	
Hawaii	Mississippi	Massachusetts	
Idaho	Missouri	Minnesota	
Iowa	North Carolina	Montana	
Kansas	Oklahoma	New Mexico	
Kentucky	Pennsylvania	New York	
Louisiana	Rhode Island	Ohio	
Maine	South Carolina	Tennessee	
Nebraska	West Virginia	Texas	
Nevada		Vermont	
New Hampshire		Virginia	
New Jersey		Wisconsin	
North Dakota			
South Dakota			
Utah			
Washington			

3 The Minimum Data Set (MDS)

All residents of Medicaid and Medicare-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 2012-2014, 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?

2.3 Methods

Our dataset covers the period between the introduction of MDS 3.0 on October 1, 2010 and December 31, 2014. 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. We include only residents in NFs on December 31, 2012, 2013, and 2014 – a census method. 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).

Note that in the 2014 National Report, we used a second method of counting which we called “new admissions” – a method that captures mostly short-term stays. The new admission method and the census method do not overlap very much (less than 20 percent) – meaning they count different sorts of people. The new admissions method generally counts residents who enter a NF for rehabilitation, and it generally misses residents who stay for long periods of time. The census method does the reverse. Because we are interested primarily in people who become long-stay residents, and because using two counting methods creates some confusion, we have decided in this version of the National Report to use just the census method.

For the census method, 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 following 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.
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 – 317-319, 758, and V79.

To compute the share of individuals who have MI, we construct the numerator as follows, 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 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 in the following way: $\frac{\text{numerator}}{\text{denominator}} \times 100$.

2.4 Findings and Discussion

Tables 8 and 9 present the national figures for nursing homes in 2012, 2013, and 2014 for specific types of PASRR disabilities, and for similar conditions as recorded in MDS diagnostic questions, listed above. Table 8 is for ID and related conditions. Table 9 is for MI. (Table 8 also appears in the Executive Summary as Table 2. Table 9 expands on Table 3 in the Executive Summary, adding the narrow definition of MI.)

Tables 8 and 9 show that in 2012-2014, 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, if not perfectly – it correctly identifies about two thirds of the individuals it potentially should identify.

Table 5: Rates of Intellectual Disabilities and Related Conditions in Nursing Homes (Year-End Census)

Year	Number of Nursing Home Residents (Census)	A1510B/C (PASRR)	A1510B/C or At Least One A1550 (PASRR or Other Dx)	A1510B/C or At Least One A1550 or At Least One I8000 (ICD) (PASRR or Other Dx)
2012	1,112,560	2.1% (22,918)	2.3% (25,540)	3.1% (34,065)
2013	1,296,579	2.2% (28,454)	2.4% (31,502)	3.2% (42,015)
2014	1,288,598	2.2% (28,531)	2.5% (31,734)	3.3% (42,134)

Table 9 shows that the pattern for individuals with MI is quite different. 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, 2013, and 2014 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 14 to 17 times greater than the number of individuals recorded as having MI in question A1510A.

Table 6: Rates of Mental Illness in Nursing Homes, Defined Broadly and Narrowly (Year-End Census)

Year	Number of Residents on Dec 31	A1510A		Broad Definition				Narrow Definition			
				A1510A or At Least One I5700-I6100 (PASRR or Other Dx)		A1510A = 1 or At Least One I5700-I6100 or At Least One I8000 (PASRR or Other Dx)		A1510A or At Least One I5700-I6100 (PASRR or Other Dx)		A1510A = 1 or At Least One I5700-I6100 or At Least One I8000 (PASRR or Other Dx)	
				#	%	#	%	#	%	#	%
2012	1,112,560	39,522	3.6%	684,140	61.5%	785,323	70.6%	215,517	19.4%	404,780	36.4%
2013	1,296,579	53,016	4.1%	807,049	62.2%	911,568	70.3%	263,561	20.3%	456,625	35.2%
2014	1,288,598	56,906	4.4%	800,530	62.1%	891,765	69.2%	259,656	20.2%	424,308	32.9%

4 General Discussion and Next Steps

Our analysis of Level I tools across the country suggests that the tools in many states are still 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 apparently fails to identify many individuals who have a recorded diagnosis of MI; at the very least, our findings are congruent with such a failure.

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. 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 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.

2.5 Next Steps: Level I

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

- Continue to 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 continue a productive conversation 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.

2.6 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 cause(s) 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.
- 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.

- Continue to help state agencies learn how to access MDS and provide ad hoc analyses upon request.

2.7 Next Steps: Quality Monitoring

In the coming year, we will turn our attention to quality monitoring and quality improvement. We will look at the systems that states have in place to track quality-related data in their PASRR programs, and to use what they find to make their programs more robust and effective. We have not yet settled on the details of our quality analysis. Once we do, we will let states know what we intend to look at, and when the results of our next analysis will first be shared with states.

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. All PTAC assistance is at no cost to states, including travel, if required. 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 PASRR 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 edward.kako@PASRRassist.org.