

PASRR Technical Assistance Center

www.pasrrassist.org



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‘Person-Centered PASRR’



Applying a Person-Centered Approach in developing the PASRR Summary of Findings Report

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Training Objectives

- ∞ To clarify federal requirements for PASRR Summary of Findings reports
- ∞ To map Summary of Findings elements to general principles of Person-Centered Planning
- ∞ To teach how to translate PASRR requirements to specific Person-Centered PASRR evaluation questions
- ∞ To demonstrate how responses to Person-Centered PASRR questions inform the Summary of Findings report and ultimately impact the individual's care plan and quality of life

Quick History for Context

- ∞ PASRR '*bottom line*' required response to 3 questions:
 - Whether the individual has a PASRR targeted condition of MI, ID, RC
 - Whether the individual needs NF
 - Whether the individual requires SS

- ∞ CMS *annual report*, in fact, only requires that states report:
Number and disposition of—
 - Residents with PASRR conditions who do not require NF but do require specialized services
 - Residents with PASRR conditions who do not require either specialized services or NF care

(Cont'd) Quick History for Context

- Many earlier state Summary of Findings (SOF) paralleled those 3 questions:
 - MH and/or ID/RC diagnosis? Y/N
 - Needs NF? Y/N
 - Needs SS? Y/N (typically no, where states restrictively define SS)



‘Mr. Smith has a PASRR Mental illness. He needs NF. He does not need SS of inpatient treatment. Admission may proceed.’

(Cont'd) Quick History for Context

∞ State PASRR Authority '*Descendants*':

- Recognize disconnect between highly complex and confusing regulations and the PASRR end product (the SOF Report)
- '*Much ado about nothing*'—Complex, high effort paper workflow process with marginal output
- '*Ham Phenomenon*'



PASRR was Hipster

∞ 7 ∞

PASRR Was Hipster

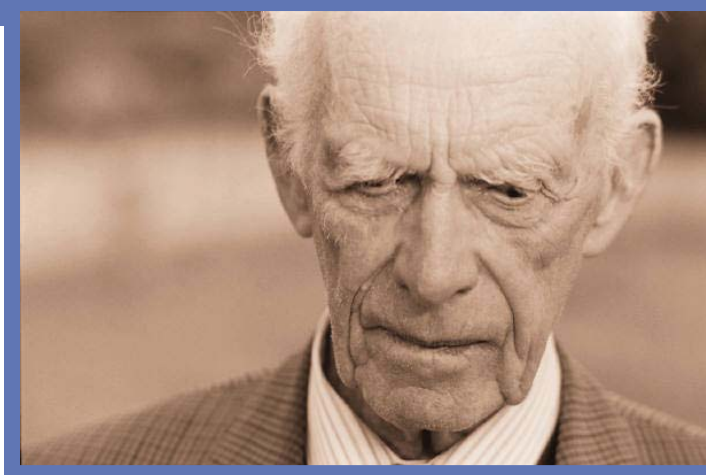
- ☞ **Actual Basis**—Rooted in understanding impact of institutionalization:
 - **Loss of skills**
 - **Tolerance for symptoms**—(symptomatic and even florid) failure to recognize symptoms or need for treatment, poor medication choices
 - **Intolerance for symptoms**—frequent discharges, overmedication
 - **IP Recidivism**



PASRR Was Hipster

∞ (Cont'd) **Actual Basis**—Rooted in understanding impact of institutionalization:

- **Staff frustration, staff turnover, or lay person dislike or fear** of residents who 'different' symptoms or behaviors
- **Resident Depression**
 - Withdrawal
 - Passive' suicide (medication or food refusal, failure to thrive)
- **Epidemic of early mortality**-versus counterparts without disability¹ (persons with mental illness die 25-30 years earlier on average)



¹Colton CW, Manderscheid RW. Prev Chronic Dis [serial online] 2006 Apr [date cited]. Available at:
URL:http://www.cdc.gov/pcd/issues/2006/apr/05_0180.htm

(Cont'd) PASRR Was Hipster

- ∞ **Actual Intention**—Develop a SOF report to minimize or, where possible, eliminate those risks:
 - Experts assess and craft an individualized report about the extent and types of services and supports needed by the individual
 - Divert and transition, when possible
 - When NF is needed, ensures the admitting nursing home can meet the person's needs through previewing the report before admission
 - Demystifies the person's condition for layperson staff—education about the person's individualized needs, presenting condition, treatments and how best to support the person
 - Uses education and information to provide a foundation for building relationships between often marginalized residents and caregivers
 - Serves as the basis for the disability portion of the person's care plan

The PASRR report represented a powerful movement forward from historically medically focused environments to individualized consideration of the needs of the person with a disability.

(Cont'd) PASRR Was Hipster

Disconnect between:

- ∞ The 3-question SOF versus the more progressive intent
'Mr. Smith has a PASRR Mental illness. He needs NF. He does not need SS of inpatient treatment. Admission may proceed.'
- ∞ Regulations were incongruent with constrictive medical model



(Cont'd) PASRR Was Hipster

∞ **Actual federal requirements** for the SOF Report to include:

1. **Medical history** [§483.128(l)(2)]
2. **Social history**, including the positive traits/strengths and developmental weaknesses/needs [§483.128(l)(2)]
3. Description of functional abilities and **level and types of support needed if the individual were to live in the community**. Whether those supports can be provided in a community setting or must be delivered in a NF. [§483.135(5)]
4. **Disability specific NF services needed** [§483.128(l)(4)] and Disability specific *specialized* services needed across a continuum [483.128(l)(5)]
5. An **explanation/rationale** [§483.128(l)(6)]
6. **Facility-specific** considerations

Fast Forward—When NF is needed for a person with a disability...

- ⌘ **Original areas of risk remain**—skill loss, tolerance, intolerance, dislike/fear, depression, premature death
- ⌘ **Ordinary life shrinks & service world is the new reality.** Crisis care dominates and the other part of the person's life fades away
- ⌘ **Where a person lives, what s/he can and can't do, and the people s/he sees each day are no longer in his/her control**
- ⌘ **Persons with disabilities risk marginalization**
 - ⌘ When symptoms or behaviors are not understood (e.g., person with a thought disorder)
 - ⌘ When communication is not understood (e.g., person with an ID/RC and many functional limitations)
 - ⌘ When preferences and needs are not understood
 - ⌘ When hopelessness sets in



Re-conceptualizing the Summary of Findings from Person-Centered Perspective

∞ 14 ∞

AKA: What you say matters

The Role of Person-Centered Assessing, Planning, and Thinking in PASRR

- ∞ **Person-centered PASRR assessment & SOF Promotes QOL and Placement Success:**
 - Helps caregivers see the individual as a **total person**, creating new ways of thinking about the person and his/her future
 - **Values and appreciates** the individual's strengths, capabilities, and contributions
 - **Engages** the person as an equal and valued expert
 - In his care plan
 - in his or her goals, preferences, and future plans
 - **Clearly identifies** an individualized and specific, full-range of formal and informal support and service needs for each individual in order to maximize placement success
 - **Advocates for the least restrictive setting** at the earliest possible time, identifying necessary supports and services needed to leverage that transition (or diversion)



Person-Centered SOF—#1 Social & Medical History

1. Social History—makes us who we are

[§483.128(l)(2)]

- ⌘ Reclaims identity
- ⌘ Powerful tool for building relationships with the provider and gaining insights into what may or may not work in terms of support or care arrangements
- ⌘ Creates connection-helps caregivers and others gain awareness of the individual as a person



(Cont'd) Person-Centered SOF—#1 Social History

∞ Examples of Social History Components (*what would you want others to know about you and your history?*)

- Family history
- Employment history
- Relationship network—formal and informal
 - Resources to pull from
 - Resources to develop
- “Road map”—
 - Reclaiming identity and roles through describing the essence of the person
 - Describing where s/he has been
 - Speaking to his/her goals, wishes, dreams—moving forward



*Celebrating and appreciating where the person has been to serve
as a basis for a plan for the future*

(Cont'd) Person-Centered SOF—#1 Social/Qualities & Strengths

1.b. Positive traits, strengths, skills

- Promote relationships, values the individual's capabilities, Informs care planning
 - **What is important to the person?** (what matters from the person's perspective?)
 - What's a good day?
 - What makes you happy?
 - Preferences?
 - Goals?
 - Specific Interests/skills?
 - **What is important for the person?** (help or support the individual needs to stay healthy, safe, and well)
 - Considerations to maximize opportunity for good days
 - Often gathered from supports who know the person well



(Cont'd) Person-Centered SOF—#1 Social/Weaknesses & Needs

1.b. Weaknesses and needs

- Levels and types of supports needed to maximize success in his/her environment
- Includes *both* QOL needs and individualized disability-specific needs
 - Day-to-day support needs
 - Communications (if nonverbal, if sparsely verbal)?
 - Interpersonal interactions?
 - Lifestyle/QOL needs?
 - Symptom management?
 - Strategies to mitigate bad days
 - What is a bad day?
 - Frustrations?
 - Symptom mitigation?

(Cont'd) Person-Centered SOF—#1 'the Story'



Especially her granddaughter, Emily.....Ada and Alison have been especially helpful to her since the death of her husband, Sam, 2 years ago from pancreatic cancer...former ballroom dance instructor and housewife. She loves big band music, and one of her favorite pastimes is watching reruns of the Lawrence Welk show...played piano and guitar.....given her an IPAD loaded with Big Band music that she listens to each morning....signs of depression....refusal to eat or take medicine, feelings of hopelessness, and loss of interest. Lost 9 lbs. in the past 3 weeks...helpful for someone to reminisce with her about her dancing days...talking about the future....particularly Emily...Skype.....

Person-Centered SOF—#2 Medical/Psychiatric History

2. Medical/Psychiatric History – [§483.128(I)(2)]

- Medical history
- Psychiatric/behavioral history
 - Educates lay caregivers about the course of that individual's disability
 - e.g., Strategies for responding to instability (what has been effective in the past)
 - Demystifies and raises disability awareness and sensitivity

(Cont'd) Person-Centered SOF—#2 Medical/Psychiatric History

∞ Examples of disability-specific information for the SOF:

- What might the lay provider see or expect? (symptom or behavior patterns)
- What does baseline with good treatment look like?
- What strategies &/or interventions have been successful in improving behaviors or mood?
- With what medications &/or treatments has s/he done best?

(Cont'd) Person-Centered SOF—#2 Medical/Psychiatric History

∞ Examples of Disability-specific information for the SOF: (Cont'd):

- What should providers **watch for**?
 - What does **unstable** look like?
 - Are there **first signs** of decline?
 - What is the typical **course**, **intensity** and **duration**?
- Have there been particular **triggers** (precursors) in the past?
- Other **measures important to promoting the health, safety and well-being** of the individual and others while the individual is a resident of the nursing facility.

(Cont'd) Person-Centered SOF—#2

Medical/Psychiatric History



When he is stable, he is very amiable...loves to play cards and is quite good at poker....when hallucinations are bothersome, helpful to engage...unstable quickly...hallucinations tell him that his medication is harmful...he'll cheek them and then spit them out...generally within 2 weeks, he will begin to decompensate....most frequently occurs during the Spring...struggles with allergies and those two seem to coincide. Can become violent...will stop trimming his thumbnails...will fill glasses partially full with water and line them on the countertop...psychiatrist evaluation...combination of old and newer generation antipsychotics...Geodon and Prolixin...contact sister, Susan...

Person-Centered SOF—#3 Functional/Supports needed for Community Living

3. Functional abilities and services/supports needed for community living–
 - Advocates for the individual
 - Identifies disability-specific services and supports needed for successful community living
 - Represents the needs of the individual
 - An expert assessment of individualized disability-specific needs and supports to transition the individual to the least restrictive environment at the earliest possible time
 - Offers synergies with community transition and diversion initiatives by identifying candidates for services
 - How does PASRR interface with MFP, Olmstead, and other community diversion services & planning?

(Cont'd) Person-Centered SOf—#3

Functional/Supports needed for Community Living

Examples of functional descriptions for the SOf:

- Types/nature/intensity of support needs to accomplish ADLs
- Types/nature/intensity support needs to accomplish IADLs
- Whether identified supports could be provided in the community or would require NF
- If NF, then whether support needs might diminish over time to permit community transition
- Any disability-specific information which might inform a transition or diversion plan
- The person's setting preference

(Cont'd) Person-Centered SOf—#3

Functional/Supports needed for Community Living



Needs help getting into and out of the tub...zipping and buckling his pants...wants to return to his sister's home...could likely transition to the community within 4-6 months with home health assistance...forgets to take his medications even with bubble packs and reminders....will need case management services or a recovery coach with particular focus on medication training and monitoring...important for NF to immediately begin working with his community case manager to begin planning for transition as soon as possible after his admission.

Person-Centered SOF—#4 Disability-Specific Services

4. Identification of the range of whatever disability-specific services and/or supports that person needs
 - Expert recommendations; Sometimes the sole disability expert to see that person
 - The expert knows about the disability; after the interviews and record reviews, the expert knows about the person
 - A full range of individualized recommendations about what services and supports are needed
 - Must be identified
 - Addressed in the care plan
 - Delivered

(Cont'd) Person-Centered SOF—#4 Disability-Specific Services

4. Considerations for SOF recommendations for disability-specific services and/or supports

- Never intended to limit recommendations to 'IP' versus 'No IP'; rather, to define an individualized range of needs
- Complicated by the many service terms—Specialized, Rehabilitative, Specialized Rehabilitative....Who's on First?
- Further complicated by payment...Who pays?
- Bottom line:

Expert identification of the range of whatever disability-specific services and/or supports that person needs

(Cont'd) Person-Centered SOF—#4 Disability-Specific Services

4. Types of disability-specific services and/or supports

- *Services*—include traditional disability-related interventions (e.g., therapies, skills trainings, adaptive technologies).
- *Supports*—include unique disability-related strategies or resources that will help an individual to be safe, healthy and successful in the nursing facility setting. (e.g., naturally occurring supports, behaviors to support and encourage, or strategies for increasing or maintaining an individual's success or competence).

(Cont'd) Person-Centered SOF—#4 Disability-Specific Services

4. CMS Guidance and Policy Clarifications

- Same requirements. New paradigm
 - Defines service and support types
 - Clarifies expectations for service delivery
 - States cannot limit SS to IP or ICF/MR
- Re-conceptualizes payment strategies
- Creative, innovative concepts
- Makes disability-specific services equal in importance to medical services



(Cont'd) Person-Centered SOF—#5 Facility-Specific Recommendations

5. Consideration of the provider's ability to meet the needs of the resident

- While some persons' needs may be 'standard', others may have **highly specific service or support needs** that cannot be met in all settings
- Advocates for the *right* setting—one that will meet the individual's unique needs
 - Facility must have the ability to meet the resident's needs (PAS)
 - Facility must commit that it will address those needs

(Cont'd) Person-Centered SOf—#4 Disability-Specific Services

...important to engage her support system for QOL interactions, ensuring she gets frequent opportunity to interact with her granddaughter, Emily, through Skype...structured opportunities to listen to Big Band music...someone to sit with and engage her while she is eating...grief therapy...evaluation for an antidepressant....closely monitor weight...talk about the future...



...educate staff about his symptoms...monitor medications, especially in the Spring....before psychotropic medication changes are considered, contact his sister, Susan, and ensure that only a psychiatrist modifies antipsychotic regimen...consistent visits with a psychiatrist...when he is bothered by hallucinations...

Person First

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It matters how you say it

A Final Thought-Person First Language

- ∞ *The difference between the right word and the almost right word is the difference between lightening and the lightning bug*
 - Mark Twain
- ∞ *If thought corrupts language, language can also corrupt thought*
 - –George Orwell

EXAMPLES OF PEOPLE FIRST LANGUAGE

BY KATHIE SNOW; VISIT WWW.DISABILITYISNATURAL.COM TO SEE THE COMPLETE ARTICLE

Remember: a disability descriptor is simply a medical diagnosis.
People First Language respectfully puts the person before the disability.
A person with a disability is more *like* people without disabilities than different.

SAY:	INSTEAD OF:
People with disabilities.	The handicapped or disabled.
He has a cognitive disability/diagnosis.	He's mentally retarded.
She has autism (or a diagnosis of...).	She's autistic.
He has Down syndrome (or a diagnosis of...).	He's Down's; a mongoloid.
She has a learning disability (diagnosis).	She's learning disabled.
He has a physical disability (diagnosis).	He's a quadriplegic/is crippled.
She's of short stature/she's a little person.	She's a dwarf/midget.
He has a mental health condition/diagnosis.	He's emotionally disturbed/mentally ill.
She uses a wheelchair/mobility chair.	She's confined to/is wheelchair bound.
He receives special ed services.	He's in special ed.
She has a developmental delay.	She's developmentally delayed.
Children without disabilities.	Normal or healthy kids.
Communicates with her eyes/device/etc.	Is non-verbal.
People we serve	Client, consumer, recipient, etc.
Congenital disability	Birth defect
Brain injury	Brain damaged
Accessible parking, hotel room, etc.	Handicapped parking, hotel room, etc.
She needs... or she uses...	She has problems with/has special needs.

Keep thinking—there are many other descriptors we need to change!

Excerpted from Kathie's People First Language article, available at [www.disabilityisnatural.com](http://WWW.DISABILITYISNATURAL.COM).

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Person First

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Kathie Snow

Person First Language-
Resource for assessors
and summary writers:

<http://www.disabilityisnatural.com>

<http://www.disabilityisnatural.com/images/PDF/pfl09.pdf>

Much ado about many

∞ 37 ∞

Little changes have potential for big impact

⌘ http://www.youtube.com/watch?feature=player_embedded&v=NKDXuCE7LeQ



References & Resources

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- ⌘ Institute on Disability. University of NH:
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PASRR *Is* Hipster

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Questions & Discussion (Think Ham)

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