

State of Missouri

Prioritization of Need Manual

Department of Mental Health, Division of Developmental Disabilities

Missouri PON Manual

Introduction

This prioritization of need (PON) tool builds on the prior hard work of many individuals and organizations. The original PON served as the foundation for this modified instrument. We then drew heavily from Connecticut's Level of Need and Resource Allocation Assessment Tool, a framework that was built on empirical evidence. Finally, additional items were included based on discussions with Missouri providers, parents and agency staff; and, published instruments including the Support Intensity Scale, the Minimum Data Set and others.

This prioritization of need tool provides the information needed to accomplish the following objectives:

- ❑ provide a global picture of a person's support needs;
- ❑ identify support needs that are **NOT** being met that places a person at risk of illness, injury or harm;
- ❑ document reasons why support needs are not being met or why support needs cannot continue to be met by current caregiver(e.g., frail caregiver).

The three elements together will guide the service plan. The PON score does not guarantee the individual will receive the requested services; it simply identifies the level of need. The service is requested through Utilization Review as a completed packet which includes the verified PON score.

This manual has been produced to assist individuals who will be completing the PON review. It is suggested that this guide be used as a reference or to help others understand some of the items included in the PON.

Situations when a PON is needed include:

- Entering a Comprehensive, Community Support or MOCDDS waiver
- Switching waivers such as when aging out of the MOCDDS waiver

If the individual already participates in the Comprehensive waiver then a PON is not required when requesting ISL, Group Home, or Shared Living services.

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General Instructions

Introduction:

- Answer every question on each page completely.
- Mark only one box per item, unless specifically directed to do otherwise. If a person falls in between two categories, decide which category best describes what is typical for the person, or how much support he/she usually requires for that item. If you are still not sure, ask someone else who knows the person well or refer to his/her current written record. At times, the person completing the form may also need to use his/her best professional judgment to choose the box which most closely reflects the person's abilities and support needs. Any additional clarifying information should be included in the service plan and each section has a designated area to add page and paragraph from the service plan where the supporting information can be located.
- An unmet need is defined as a need that cannot be met by other resources available for the person to access. This may include natural supports, state plan services, community resources, and adaptive equipment/technology. Choosing not to access available resources does not constitute an unmet need. The planning team can prepare for a change that is to occur, and make associated claims in the PON, if there is real and a specific date within the next 6 months (such as aging out of a CD child specific contract) when current supports are certain to be unavailable.

When determining if an unmet need places a person at risk of illness, injury or harm consider that harm does not have to be limited to physical harm. Harm may include a significant impact to a person's quality of life, civil rights, financial stability, etc.

- When requesting a different waiver, the PON should be completed as if the individual's current supports are not in place.
- Overnight support is defined as an individual requiring someone to verbally prompt/monitor or physically support the individual during overnight hours. It should not be endorsed if the need is only for someone to be there in case some emergency should occur (i.e., "protective oversight.") The intent here is documentation that the overnight supports are truly necessary for the regular health and safety of the individual, and that the support is adequate to meet those health and safety needs. It's possible that a claim of overnight support need could be challenged if the support seems to be primarily necessary to reduce the anxiety of family or caregivers rather than truly being necessary based on the judgment of medical professionals or previous relevant experience. For Personal Care Supports consider the supports typically needed for the past 6 months.
- In addition to exploring all funding sources, less restrictive levels of support should also be explored. Less restrictive levels of support are environments that can safely meet the basic health needs of the individual, with particular preference to natural home settings over paid residential services whenever possible.
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- Employment services may include:
 - Individualized job development and placement;
 - On-the-job training in work and work-related skills;
 - Ongoing supervision and monitoring of the person's performance on the job; and

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- Training in related skills needed to obtain and retain employment such as using community resources and public transportation; and
- Negotiation with prospective employers.

The physical and behavioral issues that would require support in the workplace would also require supports in other settings. Therefore, when considering how to show a need for employment supports, consider PON questions related to other environments in the community.

Once the PON is submitted, best practice is for the PON to be reviewed within 6 business days and either verified or returned to the TCM agency for additional information.

Example:

Kayla often refuses to get dressed, and yells at staff members when they assist her with dressing in the morning. Usually the staff are able to distract Kayla by talking about the day's activities. However, one person hands-on support is needed a few times a year to finish the task. In this case, the PON would reflect what support is typically required (Verbal prompting or monitoring), even though this is not always the case.

- The PON is to reflect the person's current support needs, that is, support typically needed in the past 6 months. Unless specifically asked to do otherwise, only consider the person's current support needs when completing the PON.
- After identifying the type of support need for each item (e.g., independent, monitoring, partial hands-on assistance, total hands-on assistance), please identify if there is an unmet need placing the person at risk of illness, injury or harm.
- There is a distinction between partial hands-on assistance and total hands-on assistance. Partial hands-on assistance means that the individual can complete some part of an activity, but requires some level of direct physical support (e.g., individual can put a blouse on, but needs assistance with buttons). Total hands-on assistance means the individual is unable to complete any part of the task.
- For any activities the person does not do in their daily life, consider how much support the person would need if they were to successfully complete the activity. This may require completing the PON to reflect on the person's total skill level, other activities the person currently does, or the statements of others who know the person well.

Example:

Nicole has lived with her parents all her life. Her mother continues to do the housework for the household as she has always done. In this case, Nicole does not do any household chores on a regular basis. However, when asked, her mother does say that Nicole has used the washing machine and occasionally helps her to do other household chores, although she needs to keep an eye on Nicole in case she gets distracted. In this case, the PON should reflect how much support Nicole would need if she were to do her own household chores (Does household chores with prompting or monitoring) versus choosing the third category (Requires hands on assistance).

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- The word “typically” is used throughout the survey to indicate what happens most often, on average, or what is usual for the person. While there is variation in everyone’s activities and daily lives, most of us can identify what usually happens or what we do most often. If asked to consider a certain time period (such as “in the past year”), it may require determining the average number of times the item occurred in this time period to find out how often it typically happens. Please mark the best choice, knowing that it may not be exactly right. Then please add the page and paragraph where the information can be located in the service plan at the end of the section.

Example:

Kevin had two grand mal seizures in March, one aura in June, and another grand mal seizure in December. The question asks the team to determine how many grand mal or convulsive seizures Kevin had in the past year. To do so, add up the total number of qualifying seizures in the past year (three) and divide by the number of months (12). In this case, Kevin’s rate of grand mal seizures would average out to less than one seizure a month.

- Even if there has been a recent increase or decrease in the number of occurrences, the same method is used to determine the average number of times any event occurred in the specified time period.
- Some items will specifically ask for a description of the circumstances surrounding the skill, behavior or health condition, or to fill in the blank. Please read all the items carefully, and if a description is asked for, provide page and paragraph where the information can be located in the service plan at the end of the specific section.
- Examples are often used to further describe an item. They are shown in parentheses (as in Question 24) or following the words such as, including, or for example (as in many of the Daily Living activities or Safety questions). These are used for explanatory reasons only, and should not be seen as an exhaustive list. Examples are also specifically given in the manual, following statements such as “examples include,” “such as,” or “for example.” Once again, these are given only as explanations, and should not be seen as an exhaustive list.
- The questions are written to be as self-explanatory as possible, with definitions and qualifying statements built into the questions. In addition, a more detailed explanation is provided for some of the items below.
- Several sections make a reference to page and paragraph the information can be located in the service plan if an unmet need is checked. This information is required to justify in the plan regarding the unmet need.

Please skip the following four sections if the individual is under the age of seven (7): Daily Living Supports, Personal Care Supports, Safety, and Unusual Behavioral Supports. **All** children **seven years** old and younger would **need support in these areas**. Needs in these areas are not specific to disability related needs.

Critical Service Situation (Questions a – g)

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* Even if a critical category is marked the entire PON must be completed to accurately reflect the needs of the individual.

This section is to be used for true critical situations that meet the criteria listed below. An individual could still receive a score of a non-critical 12 based on unmet needs identified throughout the PON even if the individual does not meet one of the critical criteria. The critical service section is not just used for residential services. It's for all critical situations regardless of the service requested.

a. A young adult aging out of Lopez or Autism waiver who needs the same level of care to maintain well-being.

Individuals age out of the MOCDDS (Lopez) waiver at age 18. Individuals meet these criteria when they age out of the respective waiver but remain in need of the services provided under that waiver.

b. An individual living in a state-operated or private Intermediate Care Facility for People with Intellectual Disabilities or a nursing facility. (Olmstead Issue)

Individuals have the right to receive services in the most integrated setting appropriate to their needs. In functional terms, this means that those persons transitioning out of habilitation centers and nursing homes have the highest priority in accessing waiver services.

Situations in which an individual has been placed in a nursing home in order to receive intensive, time limited (less than 6 months) nursing services, do not qualify under this definition.

This definition also does not include individuals residing in psychiatric institutions or Residential Care Facilities.

c. An adult with a court order or imminent court order

This item is meant to give priority to those adult individuals who are required or will imminently be ordered by a court to receive habilitative services. It also applies to situations where an adult individual served by the Division is unable to stay in his or her natural home due to court action against his or her caregiver(s). This includes a court order that prohibits an individual from remaining in the same household as a caregiver. It does not apply to individuals who have or are about to have a court ordering them to non habilitative services, including mental health treatment, orders of protection, substance abuse treatment, etc. It also does not apply to situations where the subject of an order of protection is someone other than an individual in the current residence.

A habilitative service refers to all DMH Medicaid waiver habilitative services. This is not limited to Habilitation Center Services.

d. The individual is under 18 and requires coordinated services through several agencies to avoid court action.

Coordinated services through several agencies refers to situations in which multiple governmental agencies (more than 2) meet to develop a plan of action and to define the respective responsibilities of each agency. The "court action" that this item attempts to avoid refers to Voluntary Placement Agreements (this is an agreement between a family and Children's Division; refer to Children's Division for information regarding a Voluntary Placement Agreement).

Note: Residential placement of minors is typically funded through the DSS Children's Division.

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e. A youth in the care and custody of DSS Children's Division, which has /a formal agreement in place with a division regional office (when formal agreement is ending).

This item refers to situations where there is a signed Inter Departmental Agreement (IDA) between the Division of Developmental Disabilities and the Children's Division. These agreements end at age 21, or upon release by the court from state custody and there is a continued need for the service. This does not include Child Specific Contracts.

This is a formality for individuals that are entering an IDA; it does not apply to individuals that are aging out of an IDA.

f. In need of immediate life-sustaining intervention to prevent an unplanned hospitalization or residential placement.

The intent of marking this category would be to obtain a service for an individual that would prevent an unplanned hospitalization or residential placement.

Planned hospitalization refers to hospitalizations that are already expected due to the individual's needs.

Unplanned hospitalization refers to hospitalizations caused by lack of support for the individual's needs. This would also include a psychiatric hospitalization.

The term "Residential Placement" could include group homes, ISL's, or nursing home placement. This item could be used to prioritize ISP's that included either Support or Comprehensive Waiver services, depending on the circumstances. Placement in an ISL or Host Home would be supportable only if there was documentation that this was the least restrictive environment, and that the alternative would be hospitalization.

This category can be used for the comprehensive waiver to avoid unplanned hospitalizations such as situations where there has been a change in the environment where the individuals' needs aren't met.

This item refers to situations where there is documentation that it is reasonable to conclude that the individual is at risk of serious physical harm or death in the absence of intervention. The term immediate does not preclude consideration of circumstances that will occur within 30 days of the assessment. Focus must be on the capacity of the individual's environment to meet the basic health and safety needs of the individual (including homelessness or the lack of a caregiver). The explanation for this conclusion must be clearly and persuasively documented within the ISP.

Homelessness does not necessarily warrant DMH funded Residential Placement. The individual's developmental disability has to limit their ability to be able to seek and maintain appropriate housing or they have no alternative options.

If the current housing environment is not ideal, but continues to provide for the basic physical needs of the individual, or if alternative housing is available that could meet those needs, then Division-funded residential interventions would not be required.

This item would only apply if no other options, including standard Medicaid benefits, are available that would be reasonably expected to provide the appropriate level of services and/or supervision, and if there

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is a credible risk of death or serious injury in the absence of Waiver funded services. *This could include situations where the death or incapacity of the caregiver results in a need for immediate life-sustaining intervention.*

Note: It is the practice of the Division to place individuals in the least restrictive environment that can safely meet the basic health needs of the individual, with particular preference to natural home settings over paid residential services whenever possible. There are times when this category can be marked based on projected situations if there is a very specific date within the next 6 months that the situation will occur.

g. Individual is in need of immediate services in order to protect self, another person(s) from immediate harm.

This item is meant to ensure prioritization in situations where the ISP has clearly and objectively documented that, in the absence of protective intervention funded by DD Medicaid Waiver, immediate harm will occur or has already occurred and is likely to reoccur.

This item is meant to ensure prioritization in situations where:

- 1) There has been a pattern of significant harm requiring formal medical care to the individual or other persons *Immediate harm" is defined as significant injury that would require medical treatment and which is imminent without protective intervention.*
- 2) These behaviors have all been documented to have occurred within the last 6 months.

This definition does not apply to a single isolated incident or situations where the danger of physical harm has not reached the level of requiring the attention of a medical facility or physician, or where the claim of risk is based on suspicions; the definition applies to a pattern of reoccurring incidents within the past six months.

In cases of abuse and/or neglect, law enforcement, the Division of Health and Senior Services, or the Department of Social Services are the appropriate resources

Per Guideline 31 Scoring Guideline for Non DMH Funded Emergency Services:

If an individual is receiving services funded through the County Boards or another entity providing emergency services, the Priority of Need assessment will measure the needs and supports of the individual as if those services were unavailable. In all other cases, the Priority of Need assessment is to reflect the needs and supports of the individual over the 60-90 days prior to the current assessment.

Example: Any temporary residential services funded by a County Board will not be considered when scoring the PON and will not prevent the level of support from being an unmet need.

Daily Living Supports (Questions 1 - 6)

Daily living activities include mobility in the community, taking medications, using the telephone, doing household chores, shopping and meal panning, and meal preparation and cooking.

Please check the one box which best describes how much support the person typically requires to do each activity.

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The evaluator should use his/her best professional judgment and consult with family members and others who know the person well in the event of uncertainty or if there is a lack of opportunity for the person to demonstrate his/her abilities for a particular question. As with the rest of the form, this section is assessing the person's abilities to do certain activities, not whether he/she does them in daily life. For example, if a person can vacuum and do laundry independently, but chooses not to, he/she would still have the first answer (Does household chores by self independently) checked, even if he/she is not currently doing them.

Some daily living activities represent a grouping or set of similar activities, such as household chores which may include washing dishes, laundry, and housecleaning. In such cases, the person's overall ability to do all of the typical activities falling under the heading "household chores" should be taken into consideration. Finally, there is a distinction between partial hands-on assistance and total hands-on assistance. Partial hands-on assistance means that the individual can complete some part of the activity, but requires some level of direct physical support (e.g., once food items are arranged on the table, the individual can make a sandwich). Total hands-on assistance means the individual is unable to complete any part of the task. Further explanations for selective questions are given below:

Question 1: *Mobility in the Community – Includes the ability to move around outside and in the community (Does not include any transportation needs).*

Mobility in the community does not include transportation needs. Instead, consider how the person ambulates or moves around when out in the community. If the person usually walks in the community on his/her own, but routinely uses a wheelchair when going to the mall or for longer shopping trips, check the second answer, partial hands-on assistance.

If the person uses a wheelchair for mobility, the response options are the same: independent, monitoring, partial hands-on assistance or total hands-on assistance. To be independent, the person must be able to move about independently using the wheelchair. Monitoring means the person needs occasional reminders when in the chair. Partial hands-on assistance means the person requires some assistance propelling or using the wheelchair. Total hands-on assistance means the person must be pushed everywhere.

Question 2: *Taking Medications – Includes taking the correct medication, accurate dose, and proper consistency (e.g., crushed) at the correct time or filling pillbox if used. Includes monitoring glucose level if needed.*

Question 3: *Using the telephone – Includes dialing the number and/or communication over the phone:*

Using the telephone can include either expressive or receptive communication. Thus, even if a person cannot speak, consider the person's ability to use the telephone for listening. For persons who cannot hear, consider the person's ability to use TTY or relay services. This includes the person's ability to locate or recall numbers and the ability to dial or place a call.

Question 4: *Doing Household Chores – Includes housecleaning, laundry, etc.:*

A typical response for household chores is that the person is either not allowed or chooses not to engage in household chores. In such situations, consider how much support the person would need if he/she were to successfully complete the activity.

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Question 5: *Shopping and Meal Planning – Includes planning for meals and shopping for groceries or other goods in neighborhood area:*

Shopping and meal planning also does not include transportation needs. Instead, think of the person's ability to shop without considering any possible transportation assistance to get there.

Question 6: *Meal Preparation and Cooking – Includes getting the food out of the cupboard or refrigerator, preparing food (including making food into appropriate consistency such as ground up, specified piece size, pureed, or liquefied), making cold meals (such as sandwiches or snacks), and cooking simple meals:*

A self-limited menu, personal preferences, or matters of taste do not justify an unmet need. An individual may have an unmet need if their menu is limited to only one or two items due to an individual's inability to prepare food safely. Meal preparation and cooking should include storing food safely.

Examples:

Unmet Need: An individual cannot complete their dishes or laundry independently and has no available resources to assist with this. Since not completing these tasks poses a risk for illness, injury, or harm to the individual this could be considered an unmet need.

Perceived as an unmet need but may not be: An individual cannot make their bed without support or reminders and there are no available resources to assist with this. This would **not** be considered an unmet need because the task of making the individuals bed not being completed does not lead to risk of illness, injury, or harm.

Personal Care Supports (Questions 7 – 15)

Personal care activities include dressing and undressing, bathing or showering, grooming and personal care, using the toilet, eating, chewing and swallowing, mobility inside the home, transferring, and changing position in a bed or chair. ***The description of each personal care item should be read carefully***, and each of the four choices considered before checking the one box which best describes how much support the person typically requires to do that activity. Once again, the evaluator may need to consult with someone who knows the person well, review the person's records, or use his/her best professional judgment in order to check the one box which best reflects the person's abilities for each question. This may especially be true if there is a lack of opportunity for the person to demonstrate his/her abilities in a particular area. Please note there is a clear distinction between partial hands-on assistance and total hands-on assistance. Partial hands-on assistance means that the individual can complete some part of the activity, but requires some level of direct physical support (e.g., person can put blouse on, but requires assistance with buttons). Total hands-on assistance means the individual is unable to complete any part of the task.

Examples and further descriptions are given for each question and for each answer choice. Once again, these examples are not meant to be used as an exhaustive list, but as a way to give the evaluator a better idea of what activities are covered in each question and in each answer category. Please provide page and paragraph where the information can be located in the service plan at the end of this section.

Question 7: *Dressing and Undressing – Includes ability to take clothes out of drawers, choose weather appropriate clothes, and use of fasteners:*

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If the individual requires more than ½ hour to dress because of physical limitations or requires help in getting clothes out of closets or drawers and does not have assistance available this would be an unmet need. Ignore issues of style or taste unless there is evidence that the applicant is or would be rejected by peers, employers, etc. or placed at an unknown risk (weather appropriate) without support.

Question 8: *Bathing or Showering – Includes sponge bath, tub bath or shower and water temperature regulation:*

If the individual chooses not to bathe regularly this would not be considered an unmet need unless it causes them to be rejected by their peers, employers, etc., they do not understand the reason for the need to bathe, or lack of bathing places them at a health risk.

Question 9: *Grooming and Personal Care – Includes brushing teeth or hair, shaving or applying deodorant.*

Question 10: *Using the Toilet – Includes going to the bathroom for bowel and urine elimination, wiping self, menstruation care, incontinent care, and ostomy/catheter care.*

Question 11: *Eating (includes IV, NG, G, or J tube feeding) – Includes ability to use fork or spoon from plate to mouth and to cut food. Does not include chewing and swallowing (covered below):*

If the individual takes longer than average to complete a meal (1 hour) or they routinely experience major problems such as dropping food or spilling beverages in the absence of natural supports this may be considered an unmet need.

Question 12: *Changing Position in Bed – Includes ability to turn side to side. Does not include ability to get out of bed or chair.*

Question 13: *Chewing and Swallowing – Includes ability to chew food and swallow food without choking:*

Special instructions for those people who have chewing and swallowing difficulties: Determining the presence of unmet need is difficult in the case of chewing and swallowing. An individual may have an attentive care provider, but chewing, swallowing and choking issues still occur. Unmet need is meant to capture a level of oversight that is not provided by the care provider. For individuals who have a feeding tube (IV, NG, G, or J tube) this can be marked as independent. Feeding tubes are addressed through question 11 under personal care supports and answering this as independent will not have an adverse effect on the individual's score.

Question 14: *Mobility in the Home – Includes the ability to move around inside the home or residence.:*

If the person uses a wheelchair or other assistive devices for mobility, the response options are the same: independent, monitoring, partial hands-on assistance or total hands-on assistance. To be independent, the person must be able to move about independently using the wheelchair or other assistive devices. Monitoring means the person needs occasional reminders when in the chair or using their assistive device. Partial hands-on assistance means the person requires some assistance propelling or using the wheelchair or assistive device. Total hands-on assistance means the person must be physically assisted to move everywhere.

Question 15: *Transferring – Includes ability to move from bed to a chair or to a wheelchair.*

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Examples:

Unmet Need: Someone has a choking risk and there is no caregiver in the home; this could be an unmet need.

Perceived as an unmet need but may not be: Someone who qualifies and chooses not to use state plan services or available natural supports to provide daily care; this would not be an unmet need.

Safety Supports (Questions 16 – 22)

Read each question and all examples given before checking either yes or no for each one. Examples are often given to better explain the question, but do not represent all the conditions or situations covered by any one statement. For any answers in this section which are not clear, the evaluator should use his/her professional judgment to mark the response which best describes what is typical for the person, and include any qualifying information by identifying the page and paragraph where the information is located in the service plan at the end of the section. In this section it may also be necessary to consider the person's overall skills and ability if the opportunity to assess how the person may react has not occurred to make a decision. Selective questions are further described below:

Question 16 *The person responds appropriately without prompting to basic safety issues at home – for example, evacuating the residence if there is a fire:*

This question refers to the most basic self-preservation skill and understanding during a real threat of an emergency situation. A “No” response to this question means that the person because of either physical and/or cognitive limitations would not or could not leave the home if threatened by fire or a tornado, etc. (if they were made aware). If the opportunity to test this has not occurred, consider whether the person could be taught the escape route or to respond to the existence of a fire or tornado. For persons who require verbal prompting to leave the home during a drill, consider whether they would in fact leave without the prompt if a real fire or tornado were to occur. Again, this question seeks to identify those persons who truly could not react to fire or tornado.

Question 17: *Overall, the person usually makes safe choices when at home – for example, not putting metal in a microwave or toaster, not opening the door to strangers or locking the door at night.*

Question 18: *The person always requires 2 people for transferring, fire evacuation, or positioning.*

Question 19: *The person is able to obtain necessary emergency assistance by some means – for example, dialing 911, pressing an emergency button, getting help from a neighbor, etc.:*

It does not matter how or by what means the person gets emergency help, as long as he/she can do so.

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Question 20: *The person responds appropriately to safety issues when not at home – for example, evacuating building appropriately if fire alarm goes off, staying on the sidewalk or refusing a ride from a stranger:*

If the opportunity to test this has not occurred, consider whether the person could be taught how to respond to an emergency situation in the community. For persons who require verbal prompting to respond to emergency situations in the community, consider whether they would in fact respond if a real emergency were to occur. Again, this question seeks to identify those persons who truly could not react to an emergency situation.

Question 21: *The person is able to avoid being taken advantage of financially – for example, not giving his/her money to strangers, or not giving out personal financial or social security information to strangers:*

If the person is continually purchasing over the phone or internet multiple items he/she does not need, this also indicates the person cannot avoid being taken advantage of financially. Consider the individuals' cognitive ability to understand the risks and consequences involved with financial decisions. If the individual has a payee they could still be at risk of financial exploitation and therefore this question could be applicable to them.

Question 22: *The person is able to avoid being taken advantage of sexually or is able to avoid sexual exploitation, including when at home, in the community, or with strangers:*

Consider whether the person could be taught how to respond to situations of sexual abuse or exploitation.

Examples:

Unmet Need: The individual is hearing impaired and their home is equipped with technology that will tell them that their home is on fire; however the individual does not know how to respond to the emergency this could be an unmet need.

Perceived as an unmet need but may not be: The person hears the fire alarm, evacuates the home, and can call 911 this is not an unmet need.

Behavioral Supports (Questions 23 – 33)

Behavioral health includes any behaviors or diagnosed emotional conditions requiring a service plan with action steps in the past 12 months. Descriptions or examples of each behavior or condition are included in the tool.

Some of the terminology on this tool has multiple meanings in different regions. The term Treatment Plan is used throughout the Behavioral Supports section and should be defined more globally. In this tool it is intended to be the equivalent of the individual's Individual Support Plan.

General instructions for Behavior section:

Please check "Yes" for any behaviors or diagnosed emotional conditions requiring monitoring or a treatment plan in the past year; otherwise, check "No." For each behavior or condition checked "Yes," consider the type and level of support typically needed to manage the behavior during waking hours. Then fill in the code which best reflects the type and level of support typically required for each behavior. Only one code for type of support required and one code for level of support are to be given for each behavior or condition checked "Yes." *Consider only type and level of support during waking hours*. Overnight support is captured in a different question.

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Support required is the type of support typically provided during waking hours *when this person exhibits this behavior*. If a treatment plan with action steps is actively in place to control a past/current behavior, the support required would be the waking hours support necessary to keep the behavior controlled. If two different types of support are used, write in the code for the support most frequently provided, and write in any qualifying comments in the behaviors comments box. A higher level of support may include other types of lower levels of support. For example, if verbal or gestural distraction or prompting is typically needed, it may be that monitoring may also be used part of the time. Choose the support used most frequently. Monitoring can also be used if the person's behavior is being controlled by medication or a treatment plan. Hands-on support refers to physical contact needed for support or intervention; which could be provided by one or more caregivers.

To be included, the support required must be specific to the person and their behavioral support needs. For example, monitoring can include monitoring by a person or using environmental means, such as door alarms. *However, to be included here, the monitoring must be used to address a specific behavior on the list exhibited by this person*. For example, if the door alarms are used to monitor the person's wandering behavior, they can be included as a support required for his/her wandering behavior (monitoring).

Frequency indicates the frequency of the behavior. Use your best professional judgment to indicate which code best reflects the level of support typically needed for each behavior. Support for behavior which is episodic or happens occasionally would be Code 1 or 'episodic'.

Question 23: *Bolting (Suddenly running or darting away--excludes wandering away)*

An interviewer would select "yes" only if the bolting behavior poses a credible threat to health or safety.

Questions 24: *Eating or drinking nonfood item (pica) (Includes ingestion of items or liquids not meant for food, such as paper clips, coins, detergent, dirt, cleaning solutions, etc.) and 25: Impulsive food or liquid ingestion (Includes binge eating or compulsive, rapid ingestion of large quantities of food or liquid)*

"Ingestion" is intended to reflect actual consumption, swallowing of the material.

Question 26: *Intentional property destruction:*

An interviewer would only select "yes" if the destruction is non-trivial and results in potential health or safety issues. Simple defacing of property, such as with a marker or crayon or damage to property due to incontinence or smearing feces would not be considered intentional property destruction.

Question 27: *Self-injurious behavior (Includes any behavior which harms one's physical self, such as head banging, biting/ hitting self, skin picking, scratching self, etc.):*

The interviewer is to select "yes" only for non-trivial behavior requiring at least basic first aid or medical care.

Question 28: *Severe physical assault or aggression (Can cause injury such as biting, or punching, or attacking):*

Verbal aggression and behavior that has not caused physical harm to others must not be the sole basis for marking "yes" on this item. Mild aggression might be appropriate for consideration

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on item 30, but the same behavior cannot be used to justify “yes” on both items. The intent of this question is to capture incidents of severe physical assault or aggression to others.

Question 29: *Disruptive behaviors, not aggression (Includes any behavior which disrupts or interferes with activities of the person or others):*

This item refers to behaviors requiring intervention, beyond the typical range of behaviors that would be expected of others the same age as the individual being assessed.

Question 30: *Mild physical assault, aggression or theft (Does not cause injury, such as pushing, grabbing, or spitting):*

See guidance related to question 28.

Question 31: *Opposes support or assistance that places the individual at risk of illness, injury or harm (Includes resisting care or assistance):*

This item is intended to reflect resistance to ADL’s, medication, therapeutic exercises, and physical assistance that has a credible and specific probability of harm.

Question 32: *Verbal aggression or emotional outbursts (Includes verbal threats, name calling, verbal outbursts, and temper tantrums):*

Behavior such as prolonged screaming and crying that resists redirection would be appropriate for this item.

Question 33: *Wandering away (Excludes bolting):*

Movement that remains within the sight of caregivers or that stays within pre-established boundaries is not to be used to justify a “yes” on this item. No matter the intent of wandering; whether it has an actual purpose or not, wandering from an area of safety could still place the person at risk.

Unusual Behavioral Supports (Questions 34 – 37)

Questions 34-37

Unusual behaviors in past year include specific behaviors requiring a service plan with action steps in the past year.

Question 34: *Sexually inappropriate behavior in past 12 months (Includes a wide range of behaviors such as disrobing, sexually inappropriate comments, masturbating in public, as well as sexually aggressive behavior):*

A person would only select “yes” if the behavior impacts the rights of others, and if the interviewer is able to obtain specific information regarding location, date and individuals affected. Simple interest in sexual activity or expression of affection are not the target of this item.

Question 35: *Criminal concerns in past 12 months (Includes any criminal justice issues or concerns, or problems with the law):*

Only behaviors that result in the involvement of legal authorities due to criminal concerns are to be considered for this item.

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Question 36: *Serious suicide attempt or serious threat made in the past 12 months.*

****please refer to manual for explanation****

A person would only select “yes” if a person made a **severe or extreme** attempt or threat as defined below.

Serious Suicide attempt or threat is evaluated on the **Level of Suicide Risk:**

None - no suicidal ideation

Mild - some ideation, no plan

Moderate - ideation, vague plan, low on lethality, wouldn't do it

Severe - ideation, plan is specific and potentially lethal, but caregiver perceives no real likelihood of attempt.

Extreme - ideation, plan is specific and potentially lethal, caregiver believes the individual will attempt or there is a history of actual attempts.

Example:

Sara becomes angry at Mom for fixing green beans instead of corn. Sara complains to her mom and makes the statement, “I am going to kill myself.” Mother understands that this is Sara’s attempt to express displeasure or frustration rather than an actual threat to end her life. This situation would be a “none” threat due to Sara only saying this because she was angry at mom for making green beans and she had no suicidal ideation. So “no” would be checked.

Question 37: *Attempted to/or set fires in the past 12 months:*

Attempted to/or set fires. The person must have attempted or set fires deliberately and purposefully on more than one occasion in the last 12 months. Fires started for setting-appropriate and functional purposes consistent with the individual’s development, such as lighting a scented candle, grill, or cigarette, are not the focus of this item. The intent is to identify patterns such as when sufficient oversight is not being met.

Examples:

Behavioral Supports I

Unmet Need: Elderly grandparent is providing care, while parents work, for an individual who bolts. The grandparent/caretaker is not able to physically keep up with the individual; this could be an unmet need.

Not an unmet need: A person binge eats and there is no person there that can physically support the individual; this could not be identified as an unmet need if other resources such as technology have not been tried.

Behavioral Supports II:

Unmet Need: When behaviors become so egregious to modify.

Unusual Behavioral Supports:

Perceived as an unmet need but may not be: Someone has pornography under their mattress per their choice for their own personal use and they are not inflicting on someone else. This would not be considered sexually inappropriate; this would not be an unmet need. Psychiatric or Mental Health Axis I Diagnosis (Questions 38 – 39)

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Questions 38-39

Question 38: *Diagnosed psychotic disorder (Includes schizophrenia, psychosis, schizoaffective disorder, etc. Write in formal diagnosis).*

Question 39: *Diagnosed mood disorder (Includes bipolar disorder, major depression, depressive disorder, etc. Write in formal diagnosis).*

Diagnosed psychotic disorder (question 38) or mood disorder (question 39) condition only include those psychiatric or mood disorders which have been formally diagnosed by a doctor, psychiatrist, or psychologist. This diagnosis must be identified in the person's Individual Support Plan but may or may not be listed in CIMOR. The condition can be diagnosed at any time in a person's life to be included, as long as a treatment plan is still actively in place to manage the condition. For those conditions checked "Yes," fill in the specific diagnosis found and the support typically required due to the mental illness or emotional condition. Next, fill in current status of the condition to indicate whether the condition is well controlled or stable; intermittent or episodic; or uncontrolled or currently in crisis. When determining type of support, consider waking hours only. Use the same process to determine Support Required and Current Status as was done in the Behavior Section.

Examples:

Unmet need: The individual needs counseling but has no resources available for the services needed; this could be an unmet need. Or treatment for disorder is not available locally and the individual can't travel to the treatment this could be an unmet need.

Perceived as an unmet need but may not be: The individual is exhibiting maladaptive or antisocial behaviors.

Prescribed Medical Treatments (Questions 40 – 50)

Prescribed treatment or care includes a list of different medical procedures, treatments or conditions. Check "Yes" if the treatment or care is currently prescribed for and used by the person; "No" if it is not. Then fill in how often assistance is needed with the treatment (support frequency).

The PON should reflect what typically or usually is needed. For example, if a person regularly gets an injection once a day, but once every two or three months also requires a second injection later in the day, the answer should reflect what usually is required or what is needed most often (in this case, once a day). Please provide the page and paragraph where the information can be located in the service plan at the end of the section.

Support Frequency refers to how often care or assistance is typically needed for each procedure or treatment. The descriptions given after each procedure give guidelines as to what should be considered when determining support frequency. For treatments which are not used on-going (such as a needle injection or postural drainage), support frequency, or the care or assistance needed for this procedure refers to how often the procedure is given. If a procedure is used continuously, such as an ostomy bag, support frequency refers to the amount of care associated with the procedure, such as the care and monitoring of the bag, rather than the fact that the person always uses one.

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Question 40: Artificial ventilator – This refers to mechanical ventilators which breathe for the person and are on continuously. Consider care and monitoring of ventilator.

Question 41: Catheter – If catheter is used continuously, consider catheter care only, such as insertion, removal, cleaning and emptying bag.

Question 42: Inhalation therapy or nebulizer – Consider how often each treatment is needed. This does not include oxygen.

Question 43: Needle injection – Consider how often an injection is given.

Question 44: Ostomy (colostomy or ileostomy) – Consider care related to the ostomy, such as cleaning the tube area of emptying the bag.

Question 45: Oxygen – If the oxygen is used continuously, consider how often care is needed to administer the oxygen; otherwise consider how often oxygen is needed.

Question 46: Postural Drainage/Chest PT – Consider how often postural drainage or chest PT is needed.

Question 47: Respiratory suctioning – Consider how often respiratory suctioning is needed.

Question 48: Seizure disorder care (includes grand mal or convulsive seizure).

Only grand mal or convulsive seizures in the past 12 months are to be considered in this question. If the person has had any other type of seizure activity, but no grand mal or convulsive seizures in the past year, check the first box “No.” The first box would also be checked for a person with a seizure disorder or epilepsy who has had no seizures at all in the past year. If the person has never had any type of seizure, check “No.”

Question 49: Tracheostomy – Consider care of stoma, cannula, and any other trach care.

Question 50: Tube/IV Feeding (nasogastric, G or J tube, IV) – Consider how often tube/IV feeding is required.

Example:

Unmet Need: The individual does not have the equipment available for prescribed medical treatment or support to provide the care this could be an unmet need. The individual is physically able to change catheter bag but does not have the cognitive ability to understand the risks with not changing the bag properly; this could be an unmet need.

Perceived as an unmet need but may not be: The Individual has not utilized available state plan services for prescribed medical treatments; this would not be an unmet need.

Diagnosed Health Conditions (Questions 51 – 71)

Question 51-71

Only health or medical conditions diagnosed by a licensed medical professional may be included or checked in this section. This diagnosis must be identified in the person’s Individual Support Plan but may or may not be listed in CIMOR. Any diagnosed medical conditions not

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on this list are to be written in the spaces provided. The diagnoses written in parentheses are given as examples of conditions falling under the more general diagnosis, and are not meant to be an exhaustive list.

Question 51: *Arthritis*

Question 52: *Cancer*

Question 53: *Choking that requires attention at least daily*

Question 54: *Chronic Pain*

Question 55: *Dementia/Alzheimer's disease*

Question 56: *Diabetes (controlled by diet , oral medications, or injections)*

Question 57: *Diabetes (controlled by injections given at a medical facility)*

Question 58: *Dialysis*

Questions 59, 60, 61, 62

These four items are NOT diagnosed health conditions. However, they are experiences that are often associated with one or more health issues. They are important, for example, as frequent medical visits are not only indicative of a complex health situation, but they are extremely burdensome to care providers.

Question 59: *Frequent medical visits (monthly)*

Question 60: *Frequent medical visits (weekly or more)*

Question 61: *History of suicide attempts or serious threats—active treatment plan in place*

Question 62: *Injuries and/or falls that require medical attention at least monthly*

Question 63: *Lung disease (COPD, emphysema, pulmonary edema, asthma)*

Question 64: *Ongoing open wound care*

Question 65: *Orthopedic conditions (e.g., scoliosis, hip dysplasia, contractures)*

Question 66: *Ongoing skin breakdowns*

Question 67: *Pregnancy*

Question 68: *Stroke*

Question 69: *Other neurological impairment (included meningitis, hydrocephalus, etc.)*

Questions 70 & 71: *Other*

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Examples:

Unmet Need: An unmet need would result from a lack of support for the diagnosed conditions or side effects caused by the condition. The individual does not have the equipment available for prescribed medical treatment or support to provide the care for the condition or side effects of the condition; this could be an unmet need.

Choking: the individual does not have a caregiver to support the individual daily; this could be an unmet need.

The individual has emphysema and smokes but does not have the cognitive ability to understand the risks; this could be an unmet need.

Perceived as an unmet need but may not be: The individual has to travel for dialysis once a week and cannot drive; this would not be an unmet need unless NEMT is not available.

Developmental Disability Diagnosis (Questions 72 – 81)

The items included in the section are present to provide a general description of the individual being scored.

Question 72: *Mental retardation*

Question 73: *Cerebral palsy*

Question 74: *Down syndrome*

Question 75: *Prader Willi*

Question 76: *Other chromosomal disorder (Fragile X, Klinefelter's Syndrome, etc.)*

Question 77: *Autism, Asperger's Syndrome, or pervasive developmental disorder*

Question 78: *Brain injury (TBI, ABI)*

Question 79: *Spina bifida*

Question 80 and 81: *Other*

Natural Supports (Questions 82 – 99)

Support Coordinator needs to obtain verification for these items and reference in the plan.

If the person has no natural supports, skip this section because the answers have already been set to default to no.

A primary caregiver is the person who takes primary responsibility for someone who cannot care fully for themselves. The plan should identify who the primary caregiver is and the natural support section is based off that individual.

Impact of care will be individualized based on how the person's level of need impacts the natural support; this section is not for the specific needs of the individual those are addressed throughout other sections of the PON. Appropriate completion of this section will be dependent on the quality of the justification in the plan on the part of the SC. Care should be made to make a compelling case.

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Question 82: *Death of primary caregiver*

When there are two equal caregivers for the individual this question would not apply to the death of one of them. In the event that one of two equal caregivers dies questions below may apply to the primary caregiver who is still living.

Question 83: *Primary caregiver has diagnosed terminal diagnosis:*

The same condition cannot be used as the basis for endorsement of “yes” on both items 83 and 91. Item 83 refers to illnesses where there has been a communication by a physician that a medical condition is expected to cause the demise or incapacity of the caregiver within 12 months. If there are two equal caregivers and one caregiver is diagnosed with a terminal diagnosis other questions in this section may apply to the individual’s situation.

Question 84: *Single caregiver family:* Note that this question references a single caregiver versus primary caregiver. This question is intended for families with one caregiver. One parent working and one staying at home does not classify as a single caregiver family. However, situations where one caregiver is gone for extended periods of time due to their job or military assignment may be considered as a single caregiver family.

Question 85: *Risk of removal from home as evidenced by an open Children’s Division investigation*

Question 86: *Primary caregiver has a documented intellectual disability:*

The term “Intellectual disability” is consistent only with a formal diagnosis of mental retardation (pre DSM-V) or “Intellectual disability” (DSM-V and following). It is inappropriate to use learning disabilities or Borderline Intellectual functioning as the basis for endorsement of this item.

Question 87: *Primary caregiver has a documented mental diagnosis (includes memory problems)*

Question 88: *Primary caregiver has no access to backup caregivers*

Explanation of the current family’s situation and why no backup care is in place is needed in the plan. With compelling justification included in the plan, an argument could be made to explain why there is no access to backup caregivers even when there are multiple caregivers.

Question 89: *Primary caregiver caring for an aging parent, ill spouse, or other relative with disabilities*

Question 90: *Primary caregiver works*

The primary caregiver attending school should not be considered for this question.

Question 91: *Primary caregiver has a physical disability/chronic disease/incapacitated:*

Includes drug/alcohol diagnoses as a chronic disease.

Question 92: *Primary caregiver has more than 3 children under the age of 10 living in the home.*

Question 93: *Family has no permanent home:*

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Question 94: *Family /person is at risk of losing home due to financial constraints:*

Only imminent foreclosures or evictions are to be considered for this item.

Question 95: *Primary caregiver is facing jail time:*

Only situations where there has been a legal conviction with a set date for incarceration are to be considered for this item.

Question 96: *Environment with domestic/sexual violence as evidenced by police reports.*

Question 97: *Temporary care giving arrangement:*

A temporary care-giving arrangement is one in which the person is placed in a different living environment or there is a change in caregiver as a result of an emergency situation. This arrangement is expected to be in place until long-term arrangements can be made. Example situations include the following: living with a non-relative, step-parent, friend, neighbor, prior foster parent, RCF, etc.

Question 98: *Primary caregiver lost employment:*

A “yes” must not be marked if the caregiver is not seeking employment, has not been employed for more than one year, is retired, or is not actively seeking re-employment.

Question 99: *Other*

Information marked under this category should have compelling justification in the plan to support it. Ensure that this information has not been addressed previously in the PON and is reflective of the impact to the individual's natural support.