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 (e.g., frail caregiver).

The three elements together will guide the service plan.

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.
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.

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 3 to 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).
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.

Several of the sections make reference to overnight support. Overnight support is defined as: Overnight support requires that someone physically do something in support of the person during overnight hours.
• 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.

Critical Service Situation (Questions a – g)

a. The person had been receiving significant services through division funded programs and services, is evaluated to still need the significant level of services, but is no longer eligible for the program or services due to aging out of the Lopez or Autism Waiver.

b. The person is residing in a public institution such as an intermediate care facility for individuals who have developmental disabilities, but has been assessed as eligible for home and community based services (HCBS). The person wants HCBS and has been determined appropriate to safely meet the person’s service and support needs (Olmstead issue).

c. Person is the focus of a court order or imminent court order. The person is subject to ongoing or pending legal action that requires immediate delivery of services.

d. Person is under age 18 and requires coordinated services through several agencies to avoid court action (System of Care).

e. Person is in the care and custody of Department of Social Services, Children’s Division, which has a formal agreement in place with a division regional office to fund the costs of Waiver services for the specific person (when formal agreement is ending).

f. Person requires immediate intervention due to imminent risk of otherwise entering an institution including but not limited to an ICF/DD, hospital, etc.

g. Person is in immediate need of life-sustaining services (food and shelter), protection from harm to self and/or others, and there is no alternative to division funding or provision of those services.

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.

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 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 3:**
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.

**Question 4:**
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.

**Question 5:**
Shopping and meal planning also does not include transportation needs. Instead, think of the person’s ability to shop for groceries without considering any possible transportation assistance to get there.

**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 13:**
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.

**Question 14:**
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.

**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:**
This question refers to the most basic self-preservation skill and understanding. 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 (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 19:**
It does not matter how or by what means the person gets emergency help, as long as he/she can do so.

**Question 21:**
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.
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.

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.

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; it may only be provided by one person.

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’.

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 36:

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 specific and lethal, wouldn't do it
Extreme - ideation, plan specific and lethal, will do it.

A person would only select "yes" if a person made a severe or extreme attempt or threat as defined above.

Example:
Sara becomes angry at Mom for fixing green beans instead of corn. Sara says “I am going to kill myself.” 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. The person must have attempted or set fires deliberately and purposefully on more than one occasion in the last 12 months.

Psychiatric or Mental Health Axis I Diagnosis (Questions 38 – 39)

Questions 38-39

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. 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.

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.

**Question 48:**
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.”

**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. Any diagnosed medical conditions not 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.

**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.

**Developmental Disability Diagnosis (Questions 72 – 81)**
The items included in the section are present to provide a general description of the individual being scored.

**Natural Supports (Questions 82 – 99)**

**Question 91:**
Includes drug/alcohol diagnoses as a chronic disease.

**Question 97:**
A temporary care-giving arrangement is one in which the person is placed in a different living environment 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.