

Quality of life: A Tool for Caregivers

When supporting people who cannot always tell their needs

This questionnaire is an optional tool for support team members to consider things that might improve a person's quality of life. It is designed to be completed by a caregiver, who knows the person well, when the person being supported struggles with answering questions and cannot always tell caregivers what they want or need.

People who can answer questions about their life with some or no assistance should instead use *My best life: A tool to tell others how you feel*.

While there are many tools available to help improve a person's quality of life, this tool strives to focus on things caregivers can do or observe about a person's behavior, as opposed to making assumptions about how a person feels or thinks.

Instructions

1. For each box on the following pages, select your level of agreement with the statement.
2. After completing the form, read the follow up steps at the end of this document labeled: [Using this tool to make positive changes in the person's life](#).
3. Make a plan and take actions to help the person improve their quality of life. The person should inform next steps as much as they are able to.

An example

A support strategy that might make the person's life better: The person receives support as needed through assistive technology.

Possible answers:

Strongly disagree: If caregivers have not attempted to support the person with any type of assistive technology.

Disagree: If assistive technology was tried in the past but is not currently used.

Don't know or not applicable: In this example, "don't know or not applicable" should not be selected because assistive technology support should be explored and attempted for all people who struggle to communicate.

Agree: If the person has a communication device and uses it occasionally, but not often, or if the teaching process and learning is still occurring. Keep in mind that it is common and completely normal for it to take many years to fully develop communication skills on a device.

Strongly agree: If the person has an effective communication device and uses it frequently and fluidly to communicate with caregivers. If "strongly agree" is selected, it might be more appropriate to use this tool's partner form instead, titled: *My best life: a tool to tell others how you feel*.

Possible actions to help the person: The case manager can add a new service to the person's plan, and a specialist can assist the person with identifying an effective communication device and teaching the person how to use it.

Getting started

Name of the person: _____

Date this form was completed or most recently reviewed: _____

Who helped complete this form: _____

Indicators and support strategies for caregivers to consider

The items listed below are intended to capture a wide variety of topics related to quality of life, and not every item will apply to all people. You are welcome to make adjustments to this tool as needed.

Relationships	Strongly disagree	Disagree	Don't know or not applicable	Agree	Strongly agree
The person has long-term relationships with people other than paid caregivers					
The person is given regular opportunities to celebrate and connect with people who share their culture, personal beliefs or identity					
If desired by the person, their birthday is recognized and celebrated every year by people who care about them					
At least twice per year, the person and their support team meet to identify person-centered values that are important to the person					
If needed, the person has a plan (which can be worked into other documents) for increasing positive social interactions that are associated with person-centered values, and all staff have been trained on the plan					
Staff promote and reward positive social interactions on a daily basis					
Staff have received formal training on the receptive and expressive language levels and skills of the person					
The person has a method for communicating desires and needs (that does not include interfering behaviors), that staff almost always understand or there is a written plan for helping the person develop those skills					
The person receives support as needed through assistive technology, translators, interpreters or other supports					

Self-determination and choice	Strongly disagree	Disagree	Don't know or not applicable	Agree	Strongly agree
The person either controls their own finances or, if assistance is needed, the person controls how they spend their discretionary (fun) money					
On a daily basis, the person is able to visit with non-staff people (this might include in person, on the phone, video chats, etc.) (does not include court orders or rights restrictions for safety purposes)					
The activities offered to the person reflect their cultural or other personal preferences					
The person has personal items that reflect their culture or interests (such as music, games, craft supplies, etc.)					
The person's living space is furnished and decorated the way the person wants and includes pleasant, stimulating things for the person to look at and engage with					
The person owns clothing that reflects their personal style and desired gender identity					
The person was able to make a choice on where they live, or the person has been offered additional support services to move to a new location					
The person was able to make a choice on who to live with or to live alone, or the person has been offered additional support services to move to a new location					
At least annually, the person is offered informed choice opportunities for employment services to explore a variety of employment or volunteer opportunities they may want, including opportunities to change jobs or volunteer positions					
The person decides every day how they spend their time (exceptions might include bad weather, medical care, school, etc.)					
The person has multiple options each day to decide when they will do things (this does not mean activities are offered continuously but the person should be given some choices)					
There are enough staff available to support the person's needs and choices					
The person is able to make their own choices about what foods they eat and how much they eat (does not include rights restrictions for life-threatening medical conditions)					
The person has regular opportunities to participate in the religion of their choice, has been given opportunities to explore other religions (if interested), or has the freedom to not participate in any religion					

Personal development	Strongly disagree	Disagree	Don't know or not applicable	Agree	Strongly agree
The person has a person-centered plan, a preference assessment or some other document that lists community or other activities the person is interested in					
On a daily basis, the person is offered a variety of community or other activities they might enjoy					
The person typically chooses to participate in the activities offered to them					
The person has learning objectives in their plans, chosen by the person, that include how staff will provide instruction and support					
The learning objectives can be achieved in less than one year (though they might be a step in a long-term goal)					
The person typically chooses to participate in their learning objectives					
There is a written plan (which can be worked into other documents) to help promote the person's independence					
There is a system/process for ensuring objectives and plans are implemented as written, with consistency by staff					

Rights	Strongly disagree	Disagree	Don't know or not applicable	Agree	Strongly agree
The person's rights have been explained to the person in a way that makes sense to them, or if the person struggles to understand, the person has an advocate who can support them					
At least semi-annually, the person is reminded of opportunities to connect with self-advocacy representatives or organizations					
The person is routinely educated about opportunities to participate in civic-engagement activities (examples might include voting, attending city council meetings, joining protests, getting t-shirts or signs to demonstrate solidarity with communities they support, etc.)					
If the person is interested in participating in any civic or advocacy activity, caregivers routinely support the connection (for example: transporting the person to meetings, helping the person call an advocate, etc.)					

Social inclusion	Strongly disagree	Disagree	Don't know or not applicable	Agree	Strongly agree
Several times each week, the person is offered opportunities to visit different community settings they might enjoy besides their home, school or workplace					
Several times each week, the person is offered opportunities to engage in social activities with people who are not roommates, coworkers or paid staff					
The person can decline social or community activities at any time and the team respects the person's choice (does not include rights restrictions or legal orders to do welfare checks)					
If there has been a decrease in the person's social engagement, steps have been taken to determine and address the cause, such as changes in interests, lost friendships, medical or psychological evaluations (for example: depression, dementia, pain, etc.), etc.					
At least twice annually, the person is informed of opportunities to join community organizations like recreation centers or gyms, clubs, libraries, bowling leagues, volunteer groups, etc.					
The person has opportunities, support and the necessary resources to participate in social media, if desired by the person					

Money and personal belongings	Strongly disagree	Disagree	Don't know or not applicable	Agree	Strongly agree
The person has enough income or other financial resources to get the things they need and some of the things they want, or there is a written plan to help the person become financially stable					
The person owns and has unlimited access to the personal items they value the most (for example: cell phone, bus pass, bike, video games, computer, etc.) (does not include legal orders or rights restrictions for safety)					
The person's belongings are respected by staff, roommates and visitors					
The person has multiple clothing options to choose from each day that are weather appropriate, fit well, and are free from holes or defects (unless desired by the person)					

Physical and mental health	Strongly disagree	Disagree	Don't know or not applicable	Agree	Strongly agree
The person has been given opportunities to see specialists for medical issues (for example: a pain specialist, chiropractor, psychiatrist, etc.)					
There is a written plan to maintain or improve the person's physical health					
There is a written plan to maintain or improve the person's mental health					
The person has enough physical space in their home, yard and work to support physical and mental health					
The person is offered a variety of creative ways to stay physically healthy that go beyond just eating salads and monotonous exercise (for example: going to a beautiful park to walk around or dancing to some music while making dinner)					
The person has access to culturally appropriate healthcare, as recommended by licensed health care professionals					
Translators are provided as needed for medical appointments					
The person's home is relatively clean, uncluttered, and items are kept in good repair (like carpeting, tile, drawers, cupboards, etc.)					
The person has been given information, in a way they understand, about how to protect themselves and others from infectious disease					
The people who support the person know how to recognize and respond to signs of stress					
If desired by the person, any known trauma history is recorded in the person's plans with instructions on how others can best support the person					
The people who support the person have been trained to recognize and respond to signs of trauma and understand how trauma can manifest in the person's behavior, experiences, health, etc.					

Using this tool to make positive changes in the person's life

Now that this tool is complete, review the items and discuss as a team what can be done to change or enhance the person's supports to improve their quality of life. If the support team is unsure what to do, they can:

- Seek advice from a [person-centered planning facilitator](#) (on the webpage, scroll down to the "Planning facilitators" section and click on "Regional listing of available person-centered planning facilitators" to find a facilitator near you)
- Collaborate with another organization or regional cohort where other providers or case managers might have ideas to share
- Consider if additional staffing is necessary to implement any of the ideas, and submit a request to the case manager to increase staffing when appropriate
- If frequent staff turnover is negatively effecting the person's life, visit the [DHS Workforce Shortage page](#) for ideas and resources for finding and retaining staff
- Contact DHS for technical assistance at PositiveSupports@state.mn.us.

This tool will likely need to be monitored over several months or years to ensure that the person and their team continue to assess and improve on quality of life. One way to track efforts could be to identify action steps/goals and incorporate them into the person's coordinated services and supports plan (CSSP).