Appendix B: Information about Self-Advocacy

This appendix on Self-Advocacy gives you tips on how to ask questions and find resources to satisfy your needs, preferences, and rights. You and your supportive individuals can refer to the tips when planning for services and supports. The tips are a way for you to stay involved and at the center of your care plan.

Sharing your needs with others will increase the chance that your needs will be met. There may be times when you feel like you need to share what is best for you. Speaking up lets others know what you want and need. There are many different ways to advocate for yourself or other people. Some ways may feel more comfortable to you. This tool provides some helpful tips and ideas about how to start. See Section 7: Additional Resources in this tool for other resources.

Tips to Advocate for Yourself

▶ Tip 1: Be an active participant in your care planning.

One good way to advocate for your needs and preferences is to bring together the people who support you and your interests. When your care team involves you in the care planning process, make sure to use that opportunity to share your needs! First, clarify what your goals, needs, and wishes are. Second, communicate them to others. Finally, talk to your supportive individuals about your preferences for when you go home. Talk about the services and supports you need, and who you want involved in changes to your care plan or health care.

► Tip 2: Do not be afraid to ask for help.

Many places can offer services to help both you and your supportive individuals. For example, transportation, housing, meals, support groups, and counseling services can support both you and your supportive individuals. The discharge planner and your community-based care team (for example, your case manager or navigator from a mental health or other agency) can help you find the support you need. One place is the Administration for Community Living's No Wrong Door (also known as the Aging & Disability Resource Centers) Program. More information is in the National Resources part of Section 7: Additional Resources in this tool.

► Tip 3: Slow down.

People often make decisions in a hurry. As the person receiving care, you will have many decisions to make when you return home. It is important to start the discharge planning process early. Your family member or supportive individuals may start researching your options while you are receiving care in the hospital or facility. Upon admission, seek help from your discharge planner and get support from your community-based care team (for example, your case manager or navigator from a behavioral health or other agency).

► Tip 4: You have rights!

You have the right to appeal decisions made about your treatment plan and express your concerns. For example, you might ask to change the planned discharge date, a medication decision, or a discharge referral. You have a right to be heard. Your first step is to talk with your doctor and discharge planner and share your concerns. If you have a complaint you can follow the rules of the facility where you are staying. The hospital or facility is required to let you know the steps to take to file a complaint or get your voice heard. As a last resort, you can reach out to your care team, peer supporter, Medicare, Medicaid, or your insurance company.