

DIVISION OF TENNCARE LONG TERM SERVICES AND SUPPORTS OPERATIONAL PROTOCOL

PROTOCOL TITLE: DIGNITY OF CHOICE PROTOCOL
EFFECTIVE DATE: JULY 1, 2021

OBJECTIVES

This protocol sets forth expectations for TennCare Managed Care Organizations, contracted providers, and the Department of Intellectual and Developmental Disabilities regarding philosophies and practices specific to foreseeable risk identification, assessment, and mitigation in CHOICES and I/DD MLTSS Programs, and identifies a process for addressing dignity of choice through Comprehensive Assessment, the Person-Centered Support Planning (PCSP) and Individual Support Plan (ISP) Process, and ongoing Support/Care Coordination/Case Management.

DEFINITIONS

Capacity – With support and explanation, consistent with the person’s identified communication and learning styles, the ability of the person to participate in the risk management process and identify tolerable risks. Important Note: Risk management processes must use all strategies available to empower the person to make his/her own informed decisions regarding tolerable risks.

For those persons who have an intellectual disability, cognitive impairment or substitute decision-making arrangements in place, there should be no presumption that these persons are completely incapable of participating in the risk management process. Rather, the person should be supported and involved in this process, and through this experience, the Coordinator and others in the person’s life will be able to determine the extent of the person’s capacity to fully participate in the risk management process and to identify risks that s/he feels are tolerable.

Conflict of Interest – A situation that has the potential to undermine the impartiality of a person because of the possibility of a clash between the person’s self-interest, family member’s interest, professional interest, and/or public interest.

Coordinator - For purposes of this protocol, this term encompasses Support Coordinator and Care Coordinator for CHOICES and ECF CHOICES as well as Independent Support Coordinator and DIDD Case Manager for 1915(c) Waiver Programs.

Dignity of Choice – The right of a person to make an informed decision to engage in experiences of his or her own choosing, which are necessary for personal growth and development. Supporting dignity of choice means honoring a person’s right to make choices and engage in activities that may involve risk associated with these types of choices and activities, and committing to assist the person to identify, consider, and implement strategies to mitigate the identified potential negative consequences of these choices. Per Center for Medicare and Medicaid Services (CMS), **Dignity of risk** is the idea that self-

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determination and the right to take reasonable risks are essential for dignity and self esteem and so should not be impeded by caregivers, concerned about their responsibility to ensure health and welfare.

Foreseeable Risk – The likelihood that someone would reasonably anticipate a negative outcome to occur due to one’s actions or inactions in a certain situation.

Informed Choice - Informed choice means the person is well informed to make an educated and voluntary decision about moving forward with his/her goal or planned activity after s/he has had a meaningful discussion about risks and potential outcomes, both positive and negative, that may result. *Only after the person understands how the identified risks could be mitigated can s/he make a truly informed decision about whether a particular risk is a tolerable risk that s/he wishes to accept/take.*

Having an intellectual or developmental disability does not necessarily preclude a person from being able to engage in informed choice, as decision-making abilities are individualized and can vary with the person depending on topic, skills that have been developed, or other factors. A person may be capable of understanding risk or making a choice with or without a conservator. If a person has a conservator that does not create the presumption that the person is incapable of making a choice, understanding risk, or giving consent, as each case must be assessed individually. This assessment should include a review of the conservatorship order if there is one. However, depending on the needs and strengths of the person, the person may engage decision-making support to understand potential risks and outcomes before taking action.

Natural Supports - Unpaid individuals who are involved in a person’s life, who are familiar with and have a relationship with the person, and whose opinion the person values.

Person-Centeredness – The planning process, goal identification, and risk mitigation should be person-centered, with the person actively leading or taking part in the planning of any specific outcome. Any decision regarding risk or risk mitigation should involve the person.

Risk Management – In the context of Comprehensive Assessment, PCSP and ongoing Support/Care Coordination, risk management involves identifying: (1) potential risks for a CHOICES or I/DD MLTSS Programs member ; (2) the potential positive and negative outcomes of each identified risk; (3) appropriate risk mitigation strategies that can be implemented for each identified risk; (4) the person’s tolerance for accepting/taking the identified risk given his/her goals, choices, and preferences, assuming implementation of the mitigation strategies; (5) the specific plan for implementing risk mitigation strategies for those risks the person determines are worth accepting/taking; and (6) the process for monitoring the effectiveness and continued relevance of the risk mitigation plan over time to ensure updates and changes are made as needed.

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Self-Determination – Self-determination “refers to the person’s right to make choices about their own life”¹ and is defined by the American Association of Intellectual Developmental Disabilities (AAIDD) and The Arc as, “[People with disabilities and older adults] hav[ing] the same right to, and responsibilities that accompany self-determination as everyone else. They are entitled to opportunities, respectful support, and the authority to exert control in their lives, to direct their services, and to act on their own behalf.”²

Supported Decision-Making –A way for a person with a disability to make his or her own decisions, by using friends, family members, professionals, and other people s/he trusts to:

- Help understand the issues and choices;
- Ask questions;
- Receive explanations in language he or she understands; and
- Communicate his or her decisions to others.³

Tolerable Risks – Tolerable risks are those risks a person is willing to accept/take, given their goals, choices and preferences and the risk mitigation strategies that can be applied to avoid potential negative outcomes. Effective risk management processes allow a person to make an informed decision about which risks are tolerable.

REFERENCES

A. Applicable Contractor Risk Agreement (CRA) references include:

A.2.9.6.2.3.9: As part of the enrollment visit for ECF CHOICES, TENNCARE or its designee shall, as applicable (see Section A.2.9.6.2.3.8.1) and in accordance with requirements set forth in protocol...(9) provide information regarding next steps in the process including the need for approval by TENNCARE to enroll in ECF CHOICES and the functions of the CONTRACTOR upon enrollment, including that the CONTRACTOR will work with the applicant to develop and approve a

¹ Centers for Medicare and Medicaid Services. (2019). Balancing Choice and Risk [Powerpoint slides].
² American Association on Intellectual and Developmental Disabilities. (2018). “Self-Determination: Joint Position Statement of AAIDD and The Arc.” Retrieved from <https://aaid.org/news-policy/policy/position-statements/self-determination>.
³ Francisco, Suzanne and Jonathan G. Martinis. (2017) “Supported Decision-Making Teams: Setting the Wheels in Motion.” Retrieved from <http://www.supporteddecisionmaking.org/legal-resource/supported-decision-making-teams-setting-wheels-motion>.

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PCSP in accordance with protocols developed by TENNCARE and the principles of self-determination, including dignity of choice and supported decision-making. The CONTRACTOR shall discuss with the applicant opportunities, benefits, and potential negative outcomes associated with risks that may result from the applicant’s decisions, and strategies to mitigate potential negative outcomes associated with identified risks.

- B. 2019 NCQA Standards for Long-Term Services and Supports: Case management policies and procedures specify a process for assessing a member’s physical environment and to identify risks.
- C. The Home and Community Based Services (HCBS) settings rule (CMS 2249-F/2296-F)
- D. 42 CFR 441.725 – Person-Centered Service Planning
- E. Application for 1915(c) HCBS Waiver: TN.0128, .0357, .0427 Appendix (C)-1/(C)-3 Service Specifications, Appendix D, Appendix G

BACKGROUND

Risk identification and planning to proactively mitigate identified risks are key components of comprehensive assessment and person-centered support planning. These are intended to be dynamic and ongoing processes meant to result in the identification of each person’s vision for a meaningful life. Risk planning is to take into account the person’s goals, supports available through CHOICES and I/DD MLTSS Programs, and natural supports, all of which support the person to achieve and maintain the life they want. A proactive approach to risk awareness and identification, and subsequent planning to reasonably mitigate foreseeable risks, is essential in order to avoid adopting an approach that attempts to eliminate all risk from people’s lives. An approach that attempts to eliminate all risk does not recognize that risk is a natural part of life that cannot be eradicated. There is risk in both action and inaction, in choosing to do something or not choosing to do something. Even more important, personal growth is not possible without some amount of risk. Therefore, an approach that seeks to avoid or eliminate all risk results in a person missing opportunities to grow, learn, and experience life. Instead of trying to avoid or eliminate all risks, an approach that values *dignity of choice* is essential, coupled with a commitment to identify, evaluate, and plan for mitigation of risks that come with living life and striving to reach one’s full potential.

DIGNITY OF CHOICE

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Dignity of choice is defined as recognition that a certain amount of risk is involved in all life experiences that offer the opportunity for personal growth and positive change. Supporting dignity of choice means honoring a person's right to make choices and engage in activities that may involve risk associated with these types of choices and activities, and committing to assist the person to identify, consider, and implement strategies to reduce the identified potential negative consequences of these risks.

The principle of dignity of choice closely aligns with the values of person-centered thinking and the concept of self-determination. More specifically, person-first approaches emphasize valuing the autonomy of the person, the importance of striving to assist persons to reach their full potential, and the critical importance of providing people with well-supported opportunities to learn to make good choices and informed decisions as others do: through experience, education, and practice.

In making life choices, potential risks inevitably arise. In adopting a commitment to honoring the dignity of choice, it is critically important to approach risk **without** an assumption that all risk-taking is bad. Risks are inevitable in a life that involves new opportunities for personal growth, independence, learning, relationships, employment, and other life experiences.

The discussion of risk and mitigation should focus on the person's strengths, desires, skills, and abilities. Safety is an important consideration in the decision-making process; however, it must be reasonably balanced with a person's choices, desires, preferences and needs tied to their ultimate happiness and satisfaction. While some risks may be too great to be considered tolerable by the person (i.e., those with high probability of death or serious injury), other risks (i.e., those with possibility of minor injury, negative reaction from peers, failure on first try) can be considered a part of everyday life. With a proper risk management process, the person's rights, choices, preferences and values can be respected all while maximizing the person's safety and wellbeing. In addition, people's skills and abilities change over time so that an activity unsuccessfully attempted in the past may be achievable with proper risk identification and mitigation strategies.

THE ROLE OF CARE/SUPPORT COORDINATION/CASE MANAGEMENT IN ADDRESSING RISK FOR CHOICES AND I/DD MLTSS PROGRAMS MEMBERS

In making life choices, potential risks will inevitably arise. People may need assistance from Coordinators to identify the following:

- The risk(s) associated with their choices and/or goals;
- The potential benefits and potential harm that may be associated with taking the risk(s), including taking personal responsibility in pursuing a goal or making a choice;

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- The options for mitigating the risk(s) identified; and
- Assuming the identified risk mitigation strategies are put in place, whether the person feels the identified risk(s) are worth accepting/taking, given the importance of the choice, opportunity, or goal with which the risk(s) is/are associated.

Discussion and consideration of specific risks should always balance identifying the potential benefits with the potential harm instead of only focusing on the potential harm that may result from taking a specific risk. Coordinators should be trained and possess the skills to competently assist people with the above areas, including how to collaboratively develop and implement a risk mitigation plan and to monitor the ongoing relevance and effectiveness of that plan, adjusting when necessary. Coordinators should consider innovative options for addressing risk when working collaboratively with the person to develop a risk mitigation plan. Instead of adding additional supervision or support as a means to address risk, in many situations training for the person, assistive technology or devices, coaching, or other tools may be as effective or even more effective in ensuring the person has the appropriate balance of support and autonomy.

PROTOCOL

The delivery system should work to balance health and welfare and self-determination, choice and risk. Three components of balancing choice and risk include actions to:

1. Identify and document choices and risks during initial assessment and reassessment.
2. Develop a person-centered support plan that includes individualized strategies to honor choices and address each risk.
3. Regularly revisit choice and risk discussion, analyze data (e.g. critical incident management system), monitor individual risks, and modify plans as needed.

The first step in a person-centered risk management process is identifying, through comprehensive assessment and person-centered support planning processes, the person's preferred lifestyle and vision for a meaningful life, including prioritized goals, choices, and preferences that are unique to the person. This includes encouraging and supporting the person (and involved family, conservator, or others who care about the person) to have high expectations and avoid dismissing goals and desires based on limiting assumptions about what is possible.

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Identifying Risks Unique to the Person’s Situation

The process of identifying risks includes the following information-gathering activities:

- **Interviews:** The Coordinator is to engage in conversations about risk with the person and anyone else s/he chooses to include in the person-centered planning and risk assessment process, including but not limited to, his/her family members, natural supports, and paid caregivers.
- **Observations:** Risks may be identified through observing the person’s behaviors and/or interaction with his/her environment, family, friends, peers, and/or paid caregivers.
- **Review of Records:** Risks may be identified through a record review that is a part of the PCSP process, including but not limited to: the comprehensive assessment, medical records, school records, behavioral plans, and pre-admission evaluations (PAEs).
- **Expert Advice:** Risks may be identified through conversations with professionals that support the person, including but not limited to: primary care physicians, psychiatrists, psychologists, physical therapists, occupational therapists, and behavioral therapists.

Appropriate risk identification focuses on the person’s current situation and risks relevant to that situation, recognizing that it is not appropriate to focus on risks that are not germane to the person’s current circumstances, goals, and preferences.

Determining Risk Mitigation Strategies

Once information has been gathered by the Coordinator on the potential risks associated with the person’s preferred lifestyle and vision for a good life, strategies for mitigating identified risks (including safeguards that can be put in place) should be discussed with the person and others involved in the person-centered support planning process. *Only after the person understands how the identified risks could be mitigated can s/he make a truly informed decision about whether a particular risk is a tolerable risk that s/he wishes to accept/take.*

Person-centered risk mitigation strategies take into account the following:

- All risk mitigation shall be **person-centered**, utilizing individualized supports to offer innovative solutions and least restrictive settings and practices.

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- All efforts to identify risk mitigation strategies involve **developing flexible, but prudent strategies** to promote positive risk-taking while also ensuring reasonable efforts to prevent the potential negative impact of specific risks the person wishes to accept/take.

Determining Tolerable Risks the Person Wishes to Accept/Take

- Risk planning and mitigation will take account of, and effectively support, the **person’s capacity** or ability to understand risks, including the associated benefits, potential negative outcomes, and accepting personal responsibility. Also addressed shall be the person’s ability to communicate choices and preferences including the ability to indicate which risks are considered tolerable risks.
- **Supported decision-making** is a model of decision-making which occurs when one with intellectual or cognitive challenges is the ultimate decision maker, but receives support from others who provide explanations as needed and who assist in interpreting the person’s words and/or actions to communicate his/her choices.
- When **disagreement** occurs within the support team regarding adequacy of a specific strategy for risk mitigation, it is the responsibility of the Coordinator to facilitate negotiation and utilize conflict resolution strategies to achieve agreement as to how to proceed, with a focus on balancing risk taking with a commitment to minimizing negative outcomes for the person and the community.
 - In the event the Coordinator is unable to facilitate a resolution regarding a disagreement about risk mitigation strategies, then the issue is to be promptly escalated to his/her supervisor.
 - If the Coordinator has a conflict-of-interest regarding the risk and/or facilitating the risk mitigation discussion, then s/he is to remove himself or herself from the process and involve his/her supervisor to facilitate the discussion.

Developing the Risk Mitigation Plan for Tolerable Risks

The Coordinator is to document the agreed upon plan. In order to develop a personalized and appropriate plan about risks associated with one’s activities and goals, the following information shall be discussed and documented, when appropriate:

- The identified **goal**, choice, or preference that requires a risk mitigation plan;
- Potential **positive outcomes** of taking the identified risk(s);

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- Potential **negative outcomes** of taking the identified risk(s) that the person considers tolerable;
- Potential **negative outcomes** of taking the identified risk(s) that the person considers intolerable and wishes to avoid;
- How the intolerable risk(s) will be mitigated for, including specific tasks, activities, actions, and/or decisions that will **impact** the pursuit of the goal, choice, or preference;
- How these identified activities/ actions and/or decisions that will impact the pursuit of the goal, choice, or preference will **address** the intolerable risk;
- **Who is responsible** for carrying out specific tasks and/or actions outlined in the plan;
 - The persons identified in the risk mitigation plan as being responsible for implementing outlined actions must be knowledgeable, **trained**, and competent in order to appropriately follow through with the risk mitigation strategies;
- **When** the persons identified will assist in the mitigation of the risk(s);
- What **successful** risk mitigation will look like for the person; and
- If a risk mitigation plan has already been developed, what **progress** has been made on the plan and are there new or different risks that have been identified that require a new or amended risk mitigation plan.

Note: Agencies and individual staff persons who provide HCBS in CHOICES and/or I/DD MLTSS Programs are accountable for ensuring the supports are provided in accordance with each person’s PCSP, including implementation of strategies identified to help mitigate risk, but should not be held responsible if, in spite of appropriate supports and implementation of appropriate and reasonable risk mitigation strategies, an untoward event occurs. The CHOICES and I/DD MLTSS Programs acknowledge and value dignity of choice, and recognize that the normal taking of risks in life is essential for personal growth and development and maximizing quality of life.

Keeping the Risk Mitigation Plan Current, Relevant, and Effective

- Risk and mitigation **must be reassessed** during the person-centered planning process, and may be reassessed as follows:
 - as new skills are learned or goals accomplished or changed;
 - when new services are added or existing services are changed;
 - when significant changes in needs, condition or circumstances occur;
 - after reportable event(s) occur; and/or
 - when requested by the person supported or natural supports.

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- If a new risk is identified, the severity or likelihood of a risk occurring has changed, or if earlier strategies to mitigate the risk have been unsuccessful or are no longer applicable, the process of risk assessment and mitigation planning begins again and is documented in the PCSP. The Coordinator may amend the current risk mitigation plan or start a new plan, if deemed necessary.
 - When documenting a change to the risk mitigation plan, the Coordinator should consider including information about what previously attempted strategies were or were not successful and how the plan will be adapted to suit the person’s newly identified goals, needs, or circumstances.

Note: The occurrence and reporting of a Reportable Event does not necessarily mean that the staff, provider, and/or MCO could have and should have done something differently in order to prevent the Reportable Event or reduce the negative consequences of that event on the person and others involved. The Reportable Event Management (REM) system has been intentionally designed to recognize that even when a staff person, provider, or MCO exercises due diligence, events may occur for persons supported. The CHOICES and I/DD MLTSS Programs are designed to encourage persons (with support and involvement of their families, if involved) to pursue and achieve their goals, the process for which inevitably involves taking informed, reasonable risks.

Ideally, the outcomes of acceptable risk with appropriate mitigation strategies will be an improved quality of life, personal growth, and gained confidence by those supported.

Protocol Application Example for an individual in the ECF CHOICES program⁴:

(All examples are applicable to the 1915(c) Waiver Programs with the exception of #5 and #6.)

Example #1: During the person-centered planning process, Martin has identified a goal to ride his bike to the park alone. This activity is new for Martin, and Martin and his mom, who supports Martin in some decision-making, are apprehensive about risks associated with this goal. Martin’s Support Coordinator listens to Martin’s desires and concerns, and asks follow-up questions of him and his family to better understand concerns and motivations inspiring this goal. The Support Coordinator reflects back the communicated concerns and motivations: “I understand that you hope to ride your bike to the park by

⁴ Examples included in the protocol are for training and education purposes and may not address all potential details, risks that may be encountered, or mitigation strategies that may be important to identify.

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yourself so that you can be more independent. You said you are nervous about losing your way to the park, and your mom said she is a little worried that you may have a bike accident because sometimes you are unsteady on your bike. I understand why you and your mom may feel this way, and losing your way or having an accident would be possibilities for anyone riding to the park by themselves for the first time. Even though you didn't mention this, you might also get a flat tire on your bike while you are riding by yourself. This could happen to anyone, too. Could we talk about some things we could do to address these risks, and then we can talk about how you and your mom feel about this goal?"

Losing your way: How would you feel about your mom or your support worker riding beside you for the first time? Along the way, she could point out markers – such as a store or street sign – that would show you where to turn? Can you think of other things that would be helpful to get you to the park?

Unsteady on your bike: Are there times of day when you feel less dizzy? If you take medicine in the morning, maybe late in the afternoon would be a good time. Our laws require that you wear a helmet when you ride a bike, so this would protect your head should you have an accident. How would you feel about also wearing knee pads?

Flat tire: Could you bring your cell phone with you to the park? If you have any issues with the bike, you could call your mom or support worker. We can walk through how to make the call for practice. We could also set a timer on your phone, so that when the timer goes off, it's time to start back home.

In addition, Martin discusses additional emergency scenarios with his Support Coordinator, such as getting hit by a car or if he is approached by someone looking to take advantage of him. Although there are a variety of possible scenarios to discuss, Martin and his Support Coordinator identify the scenarios Martin is most concerned about and identify mitigation strategies, as appropriate.

The Support Coordinator actively engages Martin during the discussion, and then after the risk has been discussed, the Support Coordinator confirms that Martin is still interested in the activity (informed consent). If so, Martin, Martin's mom, the Support Coordinator, the support worker, and other natural supports that Martin chooses to take part in the planning process discuss how each person will support this goal, including specific ways that Martin's mom can support the decision-making process (supported decision-making).

The Support Coordinator maintains an open dialogue with Martin after the support planning process, and can support Martin in re-evaluating this goal as needed, including identifying other mitigation strategies as needed or modifying the existing mitigation strategy as Martin gains more confidence in this task.

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Example #2: Nikki is a twenty year old young woman with a disability who needs support with making some decisions. Nikki’s mother is her conservator. Nikki spends much of her time online talking with a classmate that Nikki would describe as a love interest. Nikki’s mother is less excited about the growing relationship, and would prefer Nikki spend her time focusing on school and her part-time work. Nikki’s mother is concerned that Nikki’s interest will lead to heartbreak, declining grades as attention is taken away from school, and/or a sexual relationship that Nikki’s mother feels would be “inappropriate” for someone with a disability. During the PCSP meeting, Nikki’s Support Coordinator asks Nikki about her goals. Nikki wants to continue with school and her job, and also says “I really want Andre to be my boyfriend. He asked me to meet him at the movie theater, but my mom said no.” The Support Coordinator is aware of Nikki’s mother’s role as both a parent and conservator, but also wishes to empower Nikki and respect her wishes. The Support Coordinator has previously seen the conservatorship order, which grants Nikki’s mother authority over right of association.

Similar to Martin’s scenario above, Nikki’s Support Coordinator may engage Nikki and Nikki’s mother to better understand their respective wishes and concerns. Most parents experience apprehension when a child grows older and wishes to experience life as an adult. Additionally, Nikki may have experienced challenges with balancing responsibilities and time management in the past. She may have experienced unrequited love, and Nikki’s mother hopes to guard her against this in the future. However, Nikki may have developed additional skills or has matured and is better equipped to navigate new experiences at this point in her life. And, learning to balance responsibilities and experiencing love and companionship is a natural part of the development process.

While respecting the role of the mother/conservator, the Support Coordinator may explore risk mitigation strategies that account for both the mother and daughter’s wishes, ensuring that the mother/conservator is included in the conversation. The Support Coordinator may guide a conversation about time management and balancing the responsibilities of work, school, and friends. She may also discuss appropriate boundaries, expectations, and decision-making in romantic relationships and proactive measures to avoid pregnancy or sexually transmitted infections should Nikki choose to explore a physical relationship. The Support Coordinator and mother may jointly address these topics with Nikki to ensure she is informed and educated on potential risks. Should Nikki wish to move forward after hearing both positive and negative potential outcomes, Nikki, Nikki’s mother, and the Support Coordinator can discuss next steps. While Nikki and her mother may have differing thoughts on risks that are “tolerable,” the risk mitigation plan should address strategies that balance concerns and wishes. For example, one next steps might be weekend group outings with Andre, Nikki, and other friends while Andre and Nikki get to know each other better. The risk mitigation plan can be adjusted over time as confidence is built.

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As trust develops over time, the Support Coordinator may discuss the conservatorship in more detail with Nikki’s mother. Perhaps Nikki has developed additional skills and independence, and the conservatorship is no longer needed. The Support Coordinator can discuss options such as having Nikki’s rights restored while Nikki’s mother provides decision-making support for just those topics where Nikki needs additional support.

Example #3: Raphael has a disability and uses an Augmentive and Alternative Communication device to communicate. His direct support professional (DSP) helps him program commands and information into his device that he may need, especially when engaging in new activities. This has worked well for Raphael in the past, and Raphael likes to be as independent as possible. Raphael would like to attend a job fair without his DSP in attendance. His DSP may talk with him about potential risks, benefits, positive and negative outcomes (i.e., Raphael may feel a sense of pride and accomplishment after attending the job fair alone and networking with potential employers; Raphael may not have answers to all potential questions programmed into his device; Raphael may need to type additional answers in real-time, which can take time for Raphael to complete). After talking through the risks and benefits, Raphael decided to attend the job fair independently and talks with his DSP about mitigation strategies. For example, Raphael may have paper copies of his resume available. Or, he and the DSP may brainstorm typical questions for job fairs and ensure those answers are programmed into the device. Raphael may consider filming a short video that introduces himself and his skills to potential employers. The video can be played when meeting new people at the job fair. Following the event, Raphael and his DSP can discuss how these strategies worked and if any additional or different strategies would be helpful in the future.

Protocol Application Example for an individual in the CHOICES program:

Example #4: During the person-centered planning process, Carla discusses her decision to continue smoking cigarettes with her Care Coordinator. Even though Carla has a diagnosis of COPD and currently uses oxygen at night, she is not interested in exploring smoking cessation programs nor attempting to stop smoking at this time. Carla’s Care Coordinator acknowledges that she has the ability to make her own decisions and capacity to understand the potential consequences of continuing to smoke. The Care Coordinator and Carla discuss the hazard of smoking in the vicinity of an oxygen source and Carla states that she will take the necessary precautions to stay safe by not smoking near the oxygen source. Carla’s Care Coordinator documents this conversation in her PCSP and they agree to revisit Carla’s decision to continue smoking cigarettes at their next Care Coordination meeting.

Example #5 Valerie is meeting with her Care Coordinator during their regularly scheduled PCSP review meeting. Valerie has lived in her home for the past 30 years and receives CHOICES personal care visits to

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help her with activities of daily living. Valerie has recently started to demonstrate early signs of dementia, of which her doctors, provider, and Care Coordinator are actively monitoring.

During the meeting the Care Coordinator observes Valerie stumble over the corner of a throw rug. The Care Coordinator mentions her concern about the rug being a fall risk and suggests removing the rug. Valerie becomes agitated at this suggestion and informs the Care Coordinator that she has had that rug in her living room for the past 30 years and never once fallen because of it and doesn't plan on falling in the future. The Care Coordinator suggests the alternative of tapping down the rug corner that is raised, and again Valerie angrily dismisses her suggestion.

The Care Coordinator notes the fall risk potential in her PCSP and that Valerie is not willing to explore risk mitigation strategies at this time. The Care Coordinator makes an internal case management note to revisit the idea of tapping down the rug corner at their next Care Coordination meeting and to approach the conversation differently.

Before the next PCSP meeting, Valerie's daughter calls the Care Coordinator (Valerie has given permission for the Care Coordinator and her daughter to talk about Valerie's health care and support needs and preferences) and says Valerie went out for errands that week, but had trouble remembering how to get home. When visiting Valerie on another occasion, she notices that Valerie's pill box is unopened and she has not taken her medications. Valerie's daughter recommends that she and Care Coordinator work towards nursing home placement for Valerie. The Care Coordinator can listen thoughtfully to Valerie's daughter, understanding her concerns. One concern is that Valerie is opposed to moving. The Care Coordinator can recommend strategies to support Valerie in her home, rather than nursing home placement, so that she may stay as independent as possible. Valerie may need additional support when running errands. She may explore online grocery shopping with delivery or decision aid for Valerie when she needs assistance. The Care Coordinator may recommend an electronic or automated medication dispenser to prompt Valerie when it is time for medication. Together, they can explore options to support Valerie's unique needs so that she can continue living as independently as possible.

Example #6: Following a serious accident, Alonzo has a significant physical disability and uses an electric wheelchair. He needs help with daily activities, such as bathing and toileting. He has experienced depression and post traumatic stress disorder following the accident, and he is prescribed medication that Alonzo's doctor says will help. Alonzo agreed to try the medication, but does not want to take medication "forever." Alonzo loves baseball. He likes to use his wheelchair to travel two blocks from his home to the baseball field to watch the children's baseball games. During one game, Alonzo had an emotional reaction to fireworks. He began crying and shaking, then he began shouting at the people around him. During the

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person-centered support planning meeting, Alonzo tells his Care Coordinator about the event. He is nervous to attend another game, and says, “I’m going to throw these pills in the trash. They don’t work anyway.” Alonzo’s support worker does not want to attend a future game with him. He has recommended Alonzo try other activities with less noise. In addition, Alonzo had made a few friends at the ballfield, and after Alonzo’s reaction to the fireworks, they have pulled away from Alonzo. Alonzo’s demeanor is suppressed and withdrawn. The Care Coordinator talks with Alonzo about potential risks associated with choosing not to take the prescribed medication, as well as potential consequences (i.e., social isolation, less opportunity to connect with friends) associated with choosing not to return to the game, an activity he enjoys. Together, Alonzo and the Care Coordinator discuss opportunities to talk with Alonzo’s doctor and discuss other treatment options, including therapies that may complement the medication or provide support independent of medication use. Alonzo’s doctor may recommend a change in medication. Additionally, the Care Coordinator and Alonzo may discuss other strategies for attending a game in the future, such as attending daytime games with no fireworks. If Alonzo wishes, the support worker can be invited to the PCSP meeting to discuss his concerns with supporting Alonzo at the games, including additional training that may be needed to support someone with behavioral health needs. During the meeting, they can all discuss ways Alonzo can reconnect with friends from the ballfield, including leveraging support groups or other resources to ensure Alonzo is comfortable and well equipped to navigate the conversation with the friends and share as much information about his recovery as he is comfortable sharing.

Example #7: Terry is a person with IDD. He also has significant physical health needs and engages personal support for many activities of daily living. Terry really wants to live in an apartment of his own, but Terry’s family and Terry’s support worker have said that they think it would be very challenging for Terry to live alone. Previously, Terry received 24-hour support without the opportunity to stay alone. The family and worker have shared several concerns about his living alone: how will you get out of the building in a fire, what if you have trouble making friends in the building, what if you lose your job and cannot afford it any longer, how will you take care of your dog, Buddy Terry and his Support Coordinator have worked together on a PCSP that addresses Terry’s support needs. They have reviewed Terry’s budget and have determined that Terry has the financial means to afford the apartment and expenses. Terry really wants the support of his worker (with whom he has developed a close, trusting relationship) and his family before moving. He is concerned that his worker will find someone else to support if he goes against the worker’s recommendation. He is also concerned that his family will be displeased and will not come to visit him. The Support Coordinator can work with Terry on strategies to address the family and worker concerns, such an emergency plan to vacate the building in case of fire. She can talk with Terry about attending community events hosted by the apartment association where Terry can meet others in the building. Terry’s PCSP includes supports to assist with on the job support, and the Support Coordinator talks with Terry about outreaching to his supervisor or others for support if Terry starts to feel overwhelmed

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at his job. Terry and the Support Coordinator talk about ways that Terry can take care of Buddy while he is living alone, such as dog walking services. If Terry wishes, the Support Coordinator can help Terry initiate a conversation with the worker and family. They may even discuss how their support is still as important to Terry, even as Terry transitions to a new living environment. They can discuss their concerns in detail and Terry can share the strategies to address those concerns. It will be important for Terry to share his concerns as well and seek support during the transition and after moving, as Terry has said this is important to him in conversations with the Support Coordinator, but may not have said this to others. For example, Terry may say that he hopes the family will visit at least once a week. He may say that he values his relationship with the worker and that they can work together on any new ways that Terry may feel he needs support once living alone, such as with preparing meals. Through this conversation, Terry will feel more empowered in his decision, and each person will have a better idea of how to support Terry.