WISCONSIN DEPARTMENT
of **HEALTH SERVICES**

Using Deciding Together During the COVID-19 Pandemic

A guide to facilitate consistent and intentional communication with families in the CLTS Waiver Program

Introduction

The Wisconsin Department of Health Services (DHS) has developed this COVID-19 specific Deciding Together resource to support the continued collaboration of county waiver agencies (CWAs) and families to find new and creative solutions during this public health emergency. This resource is designed to help support and service coordinators (SSCs) to facilitate conversations with each family about their changing needs during and after the COVID-19 pandemic.

The Deciding Together framework is designed to be specific to each family, child, and situation, so guidance in this resource is intended to illustrate some of the likely common experiences of families during these times. The following content incorporates questions that may help SSCs address these added complexities families are currently facing as a result of this public health crisis.

While this conversation is family and child centered, the SSC needs to come to the discussion prepared to add ideas and insights and bring potential solutions forward. Since this guidance is specific to COVID-19 and limited to this situation, narrowing the focus of the discussion can be an important aspect of targeting family needs during this time.

Step 1: Goals and Concerns

In order to proceed with service planning, it is essential within Step 1 of Deciding Together to spend time exploring as a team (including the child or youth, family, and SSC) how COVID-19 has impacted goals and concerns for the child and family. By narrowing down and prioritizing concerns, the team is prepared to begin addressing the needs of the family and child through the remaining steps of Deciding Together.

Remember that some families do well responding to direct questions. Others may provide more information when prompted more indirectly with the use of phrasing such as:

- Tell me more about…
- Share with me…
- Help me understand…

Needs of the child or youth and family

Explore how the COVID-19 pandemic has impacted goals and issues for the child specifically and the family as a whole.

Changes due to the COVID-19 pandemic

- How has COVID-19 impacted your family?
- What is happening for you at this time?
- What are the priorities for your family to get through this time?
- What is still working well for your family?
- What else has changed for your family (for example, parent work schedules, difference in or a reduction in supports from family and friends, how the school district is supporting learning)?
- What changes have you seen to CLTS services during the pandemic?

Routines and daily life

- What happens in a "typical" day or night right now?
- What tasks/times of day/activities do you find most challenging?
- What would "better" look like right now?
- What would a good day look like right now?
- What types of activities would your family like to be able to do during this time?

Caregiver and family needs

- What opportunities are there for self-care?
- What do you and your family do to manage stress? Conflict? What does your family do when stressed out, sick of each other, bored?
- What does or might your family be able to do for physical activity?

Changes to the Individual Service Plan (ISP)

Based on responses to family questions, review the outcomes and goals with family to drive conversation surrounding these key questions.

- What would success in reaching an outcome or goal look like right now for your family?
- Have your current supports and services continued to be helpful? Would you like to review or make any changes?
- What are the top three things that would be the most helpful to you right now?
- Do you have/are you able to access your usual support systems? What have you tried to stay connected? What else might be helpful?

Communication during the public health emergency

Because service planning is an ongoing process, it is expected that communication and discussion will continue throughout the public health emergency. Establish a communication plan with the family so everyone knows what to expect. If appropriate, develop a crisis plan specific to this public health emergency when providers and services may not be available as usual.

Planning for regular communication
- What is the family's preferred method of communication?
- What kinds of communication is the family receiving from the CWA? How?
- Is the family receiving the right kinds of communication? What would they like to receive more of? Less of?
- Beyond the minimum required contacts, how often does the family want to communicate with the SSC? For example, some families may want a daily or weekly check in, some may not.
- How is communication with the family of a high-risk/vulnerable child more rigorous than with a child not at such risk?
- Do families know when they can expect to hear back from the SSC (for example, within 24 hours)?
- Do families know who they should contact if they can't reach their SSC at a certain time?

Planning for the unexpected
- What is the plan for if the family is still receiving face-to-face provider services, and the provider becomes sick, is unavailable, or doesn't show?
- What is the plan for services if a participant, family member in the home, or a provider becomes ill with COVID-19?
- What is the plan if the family is not responding to communication, especially if a high-risk or vulnerable child is involved?

Step 2: Think Creatively
It is more important than ever to explore creative ideas for how the issue or outcome in Step 1 could be addressed. Common issues for families during this time could be stress, loss of routine, missing friends, and loss of key support staff. Think creatively about how to remediate those issues. To promote more creative solutions, consider how this issue might be addressed for any other child, including a child without disabilities. Remember that during the public health crisis, responses and access to services may include new or different providers and new or different ways of accessing services than have been used in the past.

Questions to discuss
- Discuss the different options for families to access services. What would each option look like?
- How could technology and the use of remote services provide opportunities to:
  - Increase independence and connection?
  - Develop new skills?
  - Build social connections for both the child and family?
- What are the barriers to accessing services?
- Are multiple supports needed to fully support the outcome or goal?
- Does the family need to be connected to other local resources?

Potential local resources to have available

Child or youth focused resources

- Online activities and groups for children, families, and caregivers
- Summer programming options (remote and face-to-face)
- COVID-19 resources in plain language/visual representations

Food and nutrition resources

- Women, Infants, and Children (WIC) Program
- Supplemental Nutrition Assistance Program (SNAP)
- Food pantries, free meal sites
- Grocery delivery options

Economic supports

- Unemployment resources
- Financial resources
- Emergency Assistance

Community connections

- Mental health providers delivering telehealth services
- Community advocacy agencies
- Community resources (such as community centers, libraries, nonprofit agencies, religious organizations)
- Parent supports (Family Resource Centers, local support groups)

Reducing barriers to services

- Resources to help families access reliable internet service
- Resources to secure technology to utilize remote services
- Provision of respite by a sibling or neighbor
- Access to personal protective equipment (PPE)
- Transportation services

Step 3: Weigh the Options

While Step 2 challenges us to think big, outside the box, and differently, Step 3 requires us to analyze those creative ideas in an effort to narrow the options. As the public health emergency has limited access to some types of service delivery, weighing options may require considerations specific to the COVID-19 pandemic.

Face-to-face service delivery

If considering face-to-face provider services, explore and weigh the risk of exposure to COVID-19 versus the impact of service not being provided at all.

- Is there an ongoing or increased need for the service?
- What are the alternatives to face-to-face contact?
- What health conditions or vulnerabilities should be taken into consideration for the child or youth?
- What is the risk of exposure to the participant, family members, or caregivers or providers? Are there any vulnerable family members?

- What is the accessibility of PPE?
- What is the family's comfort level and preference?

Remote service delivery
- What is the family's comfort level with using technology for service delivery?
- Does the family have access to the necessary technology for remote services? If not, what are the options for obtaining this technology?
- Does the family or child need assistance to use the technology? Is there someone who can support them to do this?
- Consider and explain the Health Insurance Portability and Accountability Act (HIPAA) confidentiality issues when using remote services both in individual and group settings. Is the family comfortable with the risks to privacy?

Family and child specific considerations
- What are the child's and family's preferences?
- What strategies make the most sense for this child? This particular family? These goals?
- Does the plan suit or fit the family's culture and values?
- Is the family comfortable with this plan?
- What supports and services are likely to be effective?
- Does the plan address the current needs in a way that may prevent a larger issue, concern, or crisis down the road?

Step 4: Develop the Plan Together

ISPs are always fluid and flexible and can be changed at any time if requested by the family. A plan developed during the public health emergency might be situation specific and updated frequently to address challenges that may arise.

Step 4 is the time for the team to determine which targeted supports and services will be used:
- Identify who will provide the supports.
- Prioritize goals, establish timelines, and identify team members' responsibilities.

Step 4 is also the time to reflect with the family whether the service plan updates meet the family's requests. It is possible that even after a collaborative and engaging dialogue through the steps in Deciding Together, the family and SSC might not agree on the actions to be developed in the ISP. It is entirely possible that the family and SSC can still have different ideas about how to address the outcome or challenge. It is important to recognize the impact and balance of power each of the team members may have. Sharing appeal rights is an important, required step in ensuring families fully exercise their contribution to the decision making within the program.

If the family and SSC have different ideas about the ISP

- Stay engaged, work to understand all perspectives, and seek solutions. It is natural for people to have differences of opinion from time to time.
- Be comfortable providing information to the family about participant rights and the appeal process, which remain the same during this public health emergency.
- Remind the family that every family has the right to file for a hearing with the Division of Hearings and Appeals. SSCs are required to provide every family with information about their right to appeal (verbally and in writing) in any instance where:
    o Services are denied.
    o Services are reduced from requested amount.
    o The family's choice of provider is not approved.

It is important to explain to the family that requesting a formal appeal is not perceived as a negative action and is simply another avenue for advocating for their family.

Step 5: Evaluate Effectiveness

Steps 1 through 4 are only the beginning of Deciding Together. Once a plan is developed, the real work of monitoring the impact of that service or support and assessing the value to the child and family begins. Discuss how and when each team member will communicate the impact and value of the plan. A COVID-19 specific service plan update may warrant more targeted and/or frequent monitoring to assess effectiveness. Adjustments may need to be made during the pandemic or shortly after. Make a plan for how and when needed adjustments will be addressed.

Some considerations:

- How and when will the family and SSC evaluate the plan for success?
- Has the youth or family identified any changes in their goals, interests, or priorities?
- How well does this set of supports and services meet the child and family's needs? How well does it promote their ability to achieve their desired outcomes?
- How does the plan rigorously respond to the need of a high risk or vulnerable participant and family?

Summary

This supplemental communication resource has been created to support SSCs and families in incorporating the foundational concepts of family-centered, team-based decision making through the Deciding Together process during the public health emergency. Using the approach outlined here will ensure these interactions are more consistently experienced by all families to meet their unique needs during and after the COVID-19 pandemic.