# Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) Programmatic Handbook

## Louisiana Department of Health (LDH)

## Office for Citizens with Developmental Disabilities (OCDD)

# Handbook Table of Contents

**INTRODUCTION**

The Louisiana Developmental Disability Law (RS 28:451.1) establishes that the Office for Citizens with Developmental Disabilities within the Louisiana Department of Health (LDH) will be responsible for the programmatic leadership in the designing and developing of all developmental disabilities services provided by the department either directly or pursuant to agreements with public and private providers. The law further delineates that:

▸ The Developmental Disabilities Services System will affirm and support the principles of self-determination and full inclusion of all persons with developmental disabilities to live, work, and participate in leisure activities in their community as they choose and to the extent possible.

▸ The Office shall provide leadership in developing supports and services which promote self-determination by persons with developmental disabilities as primary decision makers in the choice and design of their services and providers, and in the control over the resources allocated to meet their personal outcomes and goals.

▸ Person and family-centered planning principles shall be used in the design and development of the support plan and in the development of procedures and practices of the system.

▸ The Office shall adopt standards for the quality of developmental disabilities services, shall disseminate those standards to persons with developmental disabilities and their families, stakeholders, and other interested parties, and shall establish mechanisms for feedback on the quality of services from persons with developmental disabilities and their families, stakeholders, and other interested parties.

The Office for Citizens with Developmental Disabilities (OCDD) currently provides programmatic oversight of all developmental disabilities residential services with the exception of private Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID). To meet the intent of the Developmental Disability Law and to facilitate enhanced quality of life outcomes for individuals residing in ICFs/IID particularly those with behavioral and medical challenges, OCDD will initiate a process to engage private ICF/IID provider agencies in a partnering to provide programmatic oversight of their programs. Not to serve as a strictly regulatory agency, such as the LDH Health Standards Section, OCDD intends to oversee to ensure that supports and services are planned and provided in a truly person-centered manner and that supports and services are having the desired outcomes. Additionally, the Office will provide technical assistance, clinical guidance, and training to facilitate the successful partnering with private ICF/IID provider agencies.

This handbook will guide the technical assistance, clinical guidance, and training components of programmatic oversight of private ICFs/IID. Key areas which will be emphasized include the following with each area having subcomponents which will be addressed with guidelines and tools for improved outcomes:

- ▸ Person-Centered Thinking and Planning
- ▸ Enhanced Behavioral Health Supports and Outcomes
- ▸ Enhanced General Health Supports and Outcomes
- ▸ Establishing a Quality Process

Key components of the programmatic unit activities will include:

- ▸ Training
- ▸ Technical Assistance
- ▸ Individual and Agency Consultation, which will include:
  - ▸ Document/Record Reviews
  - ▸ Site Visits
- ▸ Outcome review and analysis of patterns and trends in incident reporting system

Routine Training will be offered on a statewide basis throughout the year, in addition to customized training activities that may be requested by an ICF/IID. OCDD's ICF/IID Programmatic Unit (hereafter referred to within this handbook as the Programmatic Unit) will conduct routine reviews of the reporting system along with random sampling of ICFs/IID for review and site visits. However, provider agencies may at any time request consultation which will include appropriate record reviews and site visits tailored to the reason for the request. Later sections of the handbook will provide more detailed information about expectations for these activities as well as the process for making requests.

**PERSON-CENTERED THINKING AND PLANNING**

Person-Centered thinking is a set of values, skills, and tools we use to get to know someone. It is a philosophy behind service provision that supports positive control and self-direction of people's own lives. It is a deliberate method used to see the whole person and not focus on "fixing what is wrong." The tools convey the core belief that all people have gifts and talents. The skill set allows the team to keep its focus on the person who needs support and provides a mechanism to discover, describe, and assure that the person has the life he or she desires.

Person-Centered thinking allows for both planning and implementation on a day-to-day basis. It is not about creating better paper but about helping people to have better lives. It reminds us to put the person first not only in how we speak to the person (People First Language), but also in how we best support the person. It encompasses powerful discovery on an individual basis, focuses on the present, and acknowledges that we cannot provide person-centered support without engaging in person-centered processes. It is the foundation for person-centered planning.

Person-Centered planning is a process that captures learning based on the use of the person-centered thinking skills and tools. It helps those supporting the person to identify the necessary supports needed and the actions for achieving those identified supports.

There is no "right planning method" for all people and all situations. A quality plan is a promise to listen; a promise to act on what is heard; a promise to be honest; and a promise to continue discovering and honoring what is important to the person.

Core Values associated with supporting individuals to achieve personal outcomes follow:

▸ Each person defines his or her own outcomes.
▸ The planning process begins with the discovery of who the person is.
▸ The planning process builds on the important, meaningful life experiences of the person rather than with the limitation of services available.
▸ The partnership is with the person and all the important people in his or her life.
▸ Individualized supports and services are provided to assist a person to achieve his or her vision and goals.

Building the best life is a work in progress. Understanding the person and what matters most must come first. This helps us to look at how we support the person, to set the stage/context for problems, and to identify/implement effective strategies for supporting the person. This shifts the focus to the person in a more meaningful context. We always want to start with the person's strengths and build on existing opportunities. It is only after we identify and incorporate these strengths/opportunities into the individualized plan that we focus on barriers and challenges. We want to identify the barriers and challenges that get in the way and determine how we address those areas in order to remove the barriers so the person can achieve his or her individual outcomes. Barriers/Challenges may include things such as behavioral issues, mental health

conditions, medical issues, legal issues, and skills to be developed, or other environmental negatives (e.g., lack of transportation, etc.). It is easy to let the challenges overshadow the strengths; however, we must remember that everyone has strengths and sometimes challenges channeled correctly become strengths. For example, someone labeled as stubborn may be persistent. The shift in terms of focusing on a person being persistent could lead to that person working to develop skills to assist with achieving his or her own personal outcomes. We should strive to avoid "Cookie Cutter" approaches in that we are all different people; what works for one of us will not necessarily work for all of us. Person-Centered does not equate to an all or nothing type of approach. As in everyone's life, there should be a balance between what is important to a person with what is important for a person. There should be a clear understanding that with rights there are responsibilities, and we must make sure that individuals being supported understand their rights/responsibilities and that they have enough information to make informed choices/decisions.

There are a multitude of tools available that focus on structured ways to learn. Some of the tools in our toolbox might include:

- Important to/Important for sort
- Good Day/Bad Day
- Non-negotiables: Routines/Rituals
- Important Relationships
- Communication Log
- What's Working/What's not Working
- Donut
- Learning Log
- 4 + 1 question
- Matching Table

How do we take the information we have learned and develop it into a person-centered plan? There are a variety of ways to format a plan of support, but if we have done our due diligence we should be left with a one-page summary that describes the things people like and admire about the person; includes information about what matters to the person and how the person spends his or her time; and describes the types of supports the person needs. Ultimately, the person-centered plan should synthesize/summarize the most important information, highlighting individual strengths, preferences, and priorities. We should have clearly identified the person's life vision and his or her goals, and as a team, developed the strategies needed to accomplish those goals. The plan should incorporate existing connections and opportunities to achieve goals, and where barriers/challenges exist, ideas for how we will actively address and/or remove those barriers/ challenges. For areas where support may always be needed, there should be strategies (or sustained supports) to maintain/sustain those areas. We want to provide staff with information that they will use and that will become more meaningful in terms of supporting the

person. For example, we might consider formats that provide a snapshot of supports, such as nutritional guidelines and/or behavioral guidelines.

Teamwork is a vital component of person-centered planning. The team is comprised of a group of people that come together with a shared purpose and become the circle of support for the person we are supporting. It is through the team process that we work collaboratively utilizing the tools previously discussed to learn about the person, develop the support plan, implement supports, and review/modify supports as we learn new things and identify what is working and what is not working.

Person-Centered Thinking/Planning is not a one-time activity; it is a living process. We want to keep what is working to support people and change what is not working. By taking this approach, we can change things in a variety of areas. From a quality of life perspective, we would see people engaging more in the community; people participating in meaningful day activities to include leisure and/or work type of activities; people having more relationships/ community connections; and people achieving their personal goals. For individuals with more complex behavioral and medical support needs, we would see fewer crisis events; fewer high intensity behavioral incidents; and fewer medical complications/symptoms. From a system perspective, there would be less use of high-cost services and higher employee satisfaction with less staff turnover.

Several core areas will be covered in this handbook and will frame available areas for training, technical assistance, and consultation from the Programmatic Unit. These areas include:

▸ People First Language
▸ Person-Centered Tools/Toolbox
▸ Establishing and Supporting Community Connections and Relationships
▸ Supporting Meaningful Activities and Integrated Work
▸ Enhancing the Interdisciplinary Team Process
▸ Team Toolkit

**People First Language**

Louisiana's Developmental Disabilities Services System and providers of developmental disabilities services are committed to influencing society's views and treatment of people with developmental disabilities. Positive communication affirms the dignity of people with disabilities and fosters positive attitudes. A person's self-image is strongly tied to the words used to describe the person. Referring to a person with a disability by a medical diagnosis (i.e., an epileptic or a quadriplegic) or with an inappropriate age reference (i.e., referring to someone who is over age 22 years as a child) devalues and disrespects him or her as a member of society. The terms "handicapped" and "disabled" typically evoke negative feelings and create a stereotypical perception that people with disabilities are all alike. "People First Language" refers to the person first and then addresses traits or characteristics. It puts the person before the disability; it describes what a person has, not what a person is. Such positive communication is a means of bringing about acceptance and appreciation of people with disabilities.

All providers of developmental disabilities services should provide proactive leadership toward full community inclusion of people with developmental disabilities through initiatives such as the use of "People First Language." The use of "People First Language" promotes changes in societal attitudes that help to enable people with disabilities to live full lives, to feel valued, and to achieve a sense of belonging. It is only through true acceptance and appreciation that these can occur. Private provider staff have the opportunity to impact how people with disabilities are viewed, treated, and responded to in this state. It is the responsibility of all private provider staff to provide leadership by practicing and promoting the use of "People First Language" in communicating with, writing about, and referring to people with developmental disabilities. (See the listing on the next page for examples of "People First Language" provided by Kathie Snow.)

All private developmental disabilities agencies should train staff regarding the use of "People First Language" and include a "People First Language" module all new staff orientation programs.

# People First Language
Examples to Use and to Share
by Kathie Snow
https://www.disabilityisnatural.com/people-first-language.html

| Labels Not to Use... | People First Language... |
| --- | --- |
| the handicapped or the disabled | people *with* disabilities |
| the mentally retarded or he's retarded | people *with* mental retardation or he has a cognitive impairment |
| my son is autistic | my son *has* autism |
| she's a Down's; she's mongoloid | she *has* Down Syndrome |
| birth defect | *has* a congenital disability |
| Epileptic | a person *with* epilepsy |
| wheelchair bound or confined to a wheelchair | *uses* a wheelchair or a mobility chair or is a wheelchair user |
| she is developmentally delayed | she *has* a developmental delay |
| he's crippled; lame | he *has* an orthopedic disability |
| she's a dwarf (or midget) | she *has* short stature |
| mute; nonverbal | he *does not use* words to communicate |
| is learning disabled or LD | *has* a learning disability |
| afflicted with, suffers from, victim of | person who *has* ... |
| she's emotionally disturbed; she's crazy | she *has* an emotional disability |
| normal and/or healthy | a person without a disability |
| quadriplegic, paraplegic, etc. | he *has* quadriplegia, paraplegia, etc. |
| she's in Special Ed | she *receives* Special Ed services |
| handicapped parking | *accessible* parking |

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**Person-Centered Tools: Creating Your Toolbox**

In an effort to gather the best information about the person you are supporting, you must start with structured ways to gather information. This section of the handbook will provide various tools and instructions to begin the discovery process. It is not intended that every tool be used for every person, but to utilize those tools that make the most sense to get the best information about supporting each individual.

Prior to planning for supports and service needs, information must be gathered about the person. The purpose of Discovery is to identify those things that matter most to the person and to identify his or her support needs.

Discovery activities may include:

1. A review of all records relevant to the person's interest and need for supports (i.e., school records, previous assessments, and medical records),
2. Completion of needed interviews, observations, and professional assessments (i.e., OT, PT, Speech, etc.), and
3. Getting to know the person using a variety of person-focused tools.

Discovery Activities including use of any Person-Centered tools should be completed prior to any planning meeting or determination of supports to be provided. The Discovery process provides information that assists the person in determining what is most important to him or her in each life area, establishing his or her life vision, and setting personal goals. Over time, the Discovery process provides reference points as goals are achieved and replaced by new personal goals.

Discovery is a fluid process. The team leader/facilitator interacts with the person and gathers information from the person and those who know him or her best. Ideally, the team leader/ facilitator interacts and observes the person across situations:

1. At home,
2. At work (with the approval of the employer),
3. With family and friends, and
4. With all support staff.

Information gathered from those who know the person focuses on the person's perspective (not their own opinions) and clarifies information obtained directly from the person. Research shows that family members, providers and friends do not always share the same perspective as individuals on the care and supports they receive. Use of the tools in this handbook can assist in the process of gathering information from multiple individuals and maintaining the person's perspective at the core of the process.

The primary focus of Person-Centered Discovery is to assist the person in developing his or her life vision and goals, which then drives the plan development and provision of all supports and interventions. The plan is derived from the statement of the person's personal vision and goals.

The person's *Vision* can be determined by answering: "How does the person see his or her life in the next 3-5 years?" Not all individuals are able to state their vision, and the team leader/ facilitator infers the vision from the information gathered. The vision sets the tone for the entire process and considers the following:

1. Where the person will be living,
2. What the person will be doing (work as well as recreation or community life), and
3. Who will be in the person's life?

The *goals* are what the person wants to do within the next year to help him or her reach his or her vision. The goals are identified with the person and/or others that know him or her best. These are identified at the same time that the vision is determined. Examples of personal goals include:

1. Getting a specific job,
2. Taking a vacation, and
3. Joining a club.

(Note: Obtaining or maintaining supports in the ICF/IID is not an appropriate **personal** goal.)

The process of developing a vision and goals takes into account the complex nature and multiple needs and roles of ALL persons. ALL individuals have multidimensional lives with themes that are important to them in multiple life areas.

Important To :
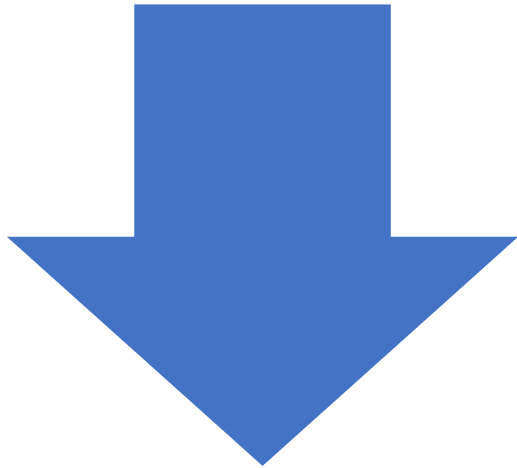
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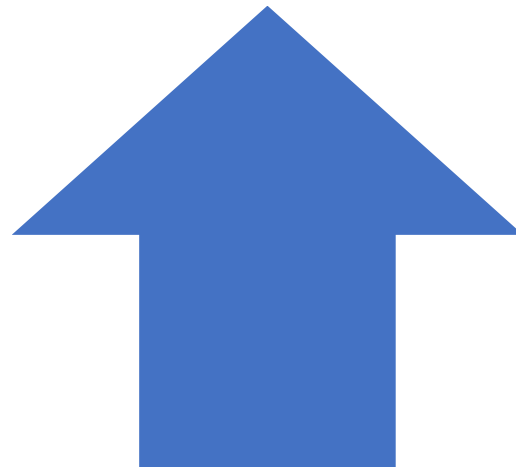
# COMMUNICATION LOG

**Person's Name:**                                                                    **Date:**

| When this happens: | I do this: | It usually means: | I want you to: |
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**Person's Name:**                                                **Date:**

| Perspective | What's Working | What's not Working |
|---|---|---|
| **Person** | | |
| **Family/Natural Supports** | | |
| **Staff** | | |

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**Donut: Understanding Our Core Responsibilities**

Not Our Paid Responsibility

Flexibility

Core Responsibilities
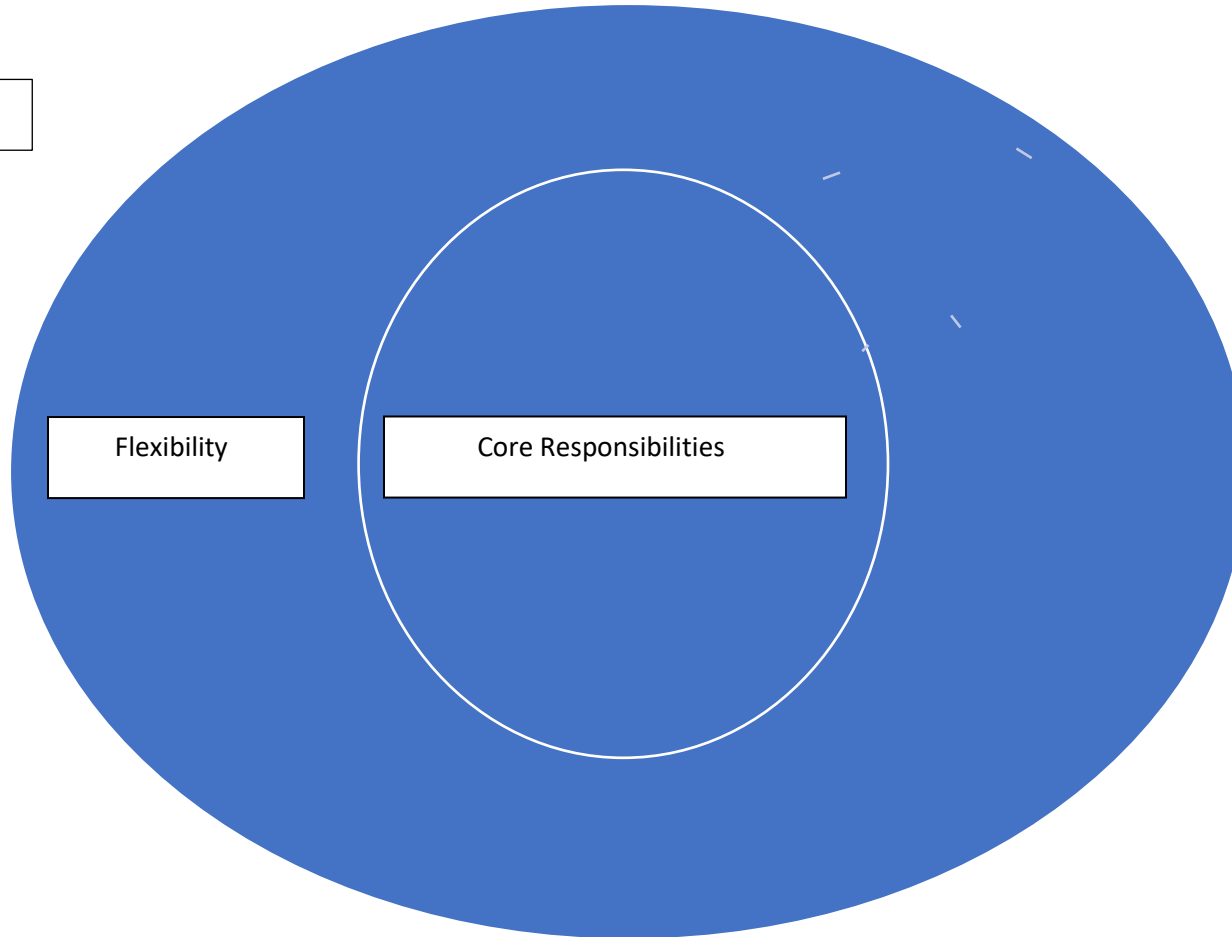
**LEARNING LOG**

**Person's Name:**

| Date | What did the person do? *(What, where, when, how long, etc.)* | Who was there? *(Names of staff, friends, others, etc.)* | What did you learn about what worked well? What did the person like about the activity? What needs to stay the same? | What did you learn about what didn't work well? What did the person not like about the activity? What needs to be different? |
|------|------|------|------|------|
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|      |      |      |      |      |
|      |      |      |      |      |

# MATCHING STAFF TOOL

**Person's Name:**                                                                                                    **Date:**

| Supports wanted and needed | Skills needed | Personality characteristics needed | Shared interests *(nice to have)* |
|---|---|---|---|
|  |  |  |  |

**Establishing and Supporting Community Connections and Relationships**

People and connections matter to some degree to each person, and it is important to look at who is involved in the person's life. Considering relationships and connections allows us to do the following:

1. Gives us a picture of who is in someone's life and who they care about,
2. Gives us ideas about who we should talk to in order to develop a good picture of what is important to the person,
3. Helps us to see balance of natural relationships/connections with those that are paid, and
4. Helps us to see richness (or lack of) relationships in person's life.

Building relationships and supporting community connections allow the person to accomplish the following:

1. Build lasting relationships,
2. Play different social roles,
3. Stabilize his or her care since there is less turnover in natural and community supports,
4. Reduce isolation, and
5. Enhance integration and independence.

Supporting the person's existing relationships and assisting him/her to build community connections starts with thinking about the following:

1. Family and friends,
2. Neighbors, church members, support organizations, and volunteers, and
3. Community classes and organizations.

When individuals have strong personal relationships and community connections they begin to move beyond a "good but paid life" and toward a community life or a life that looks more like yours and mine. For individuals with more complex behavioral and general health support needs, strong relationships and community connections can aid in improved outcomes and stability as follows:

1. Connections and Relationships "support"
   a. Enduring a painful or scary medical procedure
   b. Handling remorse following behavioral episode
   c. "Sticking it out" through difficult times; avoiding feeling of "abandonment"
   d. Providing encouragement to try learning new and perhaps difficult things
   e. Providing stability that allows one to withstand the "bumps" in the road

2. Connections and Relationships "motivate"
   a. May be "reason" for staying healthy
   b. Serve as role models
   c. Can be bridge for independence

Later sections of this handbook, will discuss in more detail behavioral and general health outcomes and supports.

Support Teams should use the Relationship Circle as a starting point for considering the person's current and desired relationships and connections. The Relationship Circle allows the team to do the following:

1. Identify gaps in relationship circle
   a. Paid vs not paid balance
   b. No one in closest circle
   c. Relationships specifically identified as important

2. Look for connections consistent with interests
   a. Community activities/organizations
   b. Groups/clubs

3. Maintain and nurture existing connections
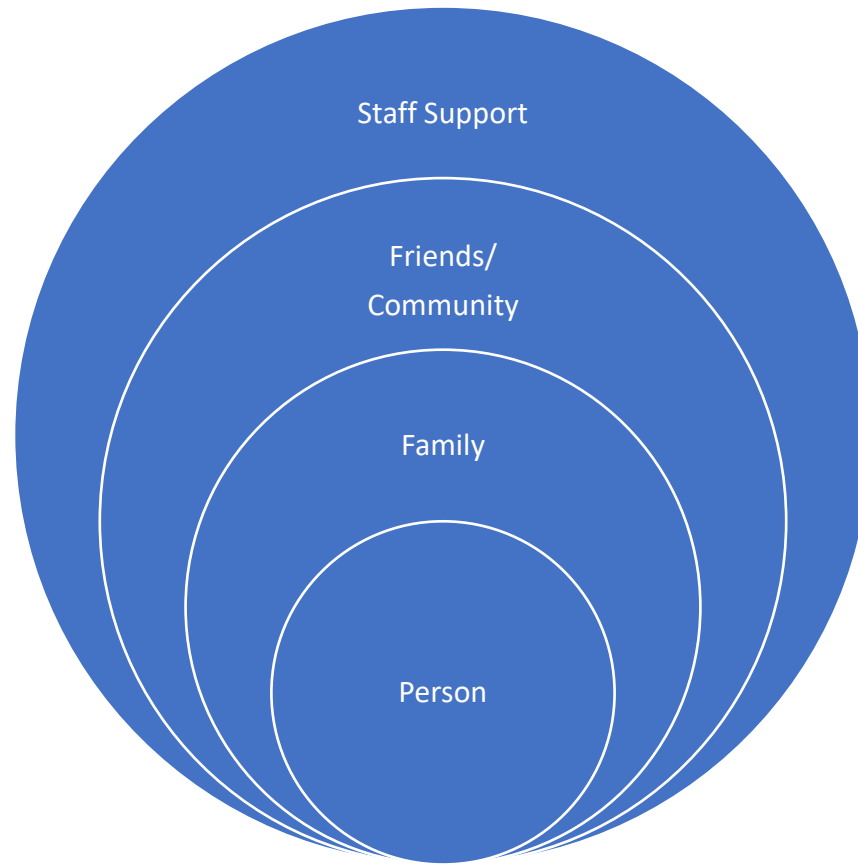
**Supporting Meaningful Activities and Integrated Work**

Every individual needs access to meaningful things to do throughout his or her day. These activities should include both academic/vocational activities and leisure/fun activities. Meaningful activity should be defined by the individual even in situations where multiple people are living together and/or for persons that do not use words to communicate. People that do not communicate with words often provide clues related to the things that matter to them via behavior. This might be a smile, turning away from an activity, falling asleep during the activity, not wanting to leave or appearing stubborn about leaving, etc.

It is important to note that there may be times when as a team we have to be creative about not only identifying the meaningful activity, but also logistically how we provide those opportunities. This means from a planning perspective we have to evaluate resources needed to accomplish these types of supports and then develop individual plans. This may mean facilitating honest/realistic discussions with the person and assisting him or her with prioritizing what matters most. It should not be all or nothing; we should be assisting the person through planning/decision making as all people must do. This means that even though I may not want to work, in order to go to the movies, go shopping, etc. I have to work in order to do these things.

It is important to remember that for individuals with more complex behavioral and general health needs having no symptoms/problems is NOT pre-requisite for meaningful work or fun activities. Specific exceptions surround dangerous/high risk situations, which may include the following, should be **verified by an appropriate professional:**

1. Actively psychotic in disruptive manner,
2. Actively manic in disruptive manner,
3. Violence at dangerous level/unpredictable,
4. Serious immune suppression, and/or
5. Very contagious medical issue.

Having access to appropriate meaningful activities can have a positive impact on an individual behaviorally and from a general health perspective in the following ways:

1. Is enjoyable and rewarding,
2. Serves as motivator,
3. (Money) supports accessing more positives,
4. Is alternative to "illegal" choices; avoids "boredom" and the need to "find" something to occupy time,
5. Shifts focus from pain/discomfort,
6. Serves as motivator for other things that must be compromised, and/or
7. May help purchase "non-covered" substitutes for non-negotiables/preferences.

**EVALUATING MEANINGFUL ENGAGEMENT AND ACTIVITIES**

**Person's Name:**                                                                                  **Date:**

| Environmental Interaction<br><br>**Type of Activity:**<br><br>Age-appropriate: _____<br><br>Age-inappropriate: _____<br><br>Engaged: _____<br><br>Non-adaptive: _____<br><br>Aggressive/Disruptive: _____<br><br>Engaged in self-care task: _____<br><br>Watching television: _____<br><br>Other activity: _____ [Specify: _____] | Observations | Opportunities for choice observed during session:<br><br>1.<br><br>2<br><br>3.<br><br>4.<br><br>5. | Comments, concerns, or suggestions for staff: |
|---|---|---|---|

**Enhancing the Interdisciplinary Team Process**

*Establishing the Support Team and Team Roles:*

The team leader/facilitator assists the person in the development of a support plan with his or her support team. The objective of the planning process is finding and acquiring supports that have real potential to put positive outcomes in the person's life based upon his or her vision and goals.

**The primary team member is the person**.

The team leader/facilitator reviews the support team membership with the person during the Discovery process and assists the person in identifying his or her support team and who should attend the planning meeting. The team leader/facilitator assures that the person understands the role of the support team to ensure that they choose the people needed.

Required team members include the team leader/facilitator, a direct service staff member, and the person's legal guardian, if applicable. If the person attends a day program or receives vocational services from another provider, a representative from his or her vocational/day program provider is also included.

Team members may also include family or friends, professionals providing supports, and any other person who knows the person best. These other team members are decided on by the person in conjunction with the core team.

Each member of the support team has specific roles and responsibilities to assist the person in achieving his or her vision and goals.

1. The role of the **person** (and family) includes:

   a. Participate in activities during the Discovery process to provide information regarding his or her (the person's) wants and needs (Note: The person may guide this process as much as he or she wishes to up to and including completing some tools him or herself.),
   b. Advocate for himself/herself in the planning process,
   c. Attend the planning meeting(s) and participate in the plan development,
   d. Be accountable for cooperating with agreed upon plan and agreed upon responsibilities within the plan,
   e. Acknowledge his or her rights and responsibilities in the planning and receipt of service,
   f. Verify any interdiction or guardianship with documentation if applicable,
   g. Attend meetings to review the plan including providing ongoing updates to vision and goals, and
   h. Comment on satisfaction with services.

2. The role of the **team leader/facilitator** in the planning process minimally includes: (Note: All Title XIX regulatory requirements must be followed and are not specified here; additionally, each provider may be organized differently and assign additional responsibilities to staff.)

   a. Coordinate the planning process,
   b. Facilitate the planning meeting and plan development including preparation of a draft of the plan in the required format,
   c. Assure development of the full array of supports needed to assist the person,
   d. Revise the plan as needed, and
   e. Provide information to other team members as needed throughout the process.

3. The role of the **direct service staff** (and any supervisory staff involved) includes:

   a. Participate in interviews, etc. during the Discovery process to provide information regarding the person's wants and needs,
   b. Attend the planning meeting(s) and participate in the plan development,
   c. (For supervisory staff) Assure staff are trained to adequately implement the plan,
   d. Implement the plan,
   e. Complete documentation as per agreement in the plan (i.e., action steps and sustained supports, critical incident reporting, major life changes),
   f. (For supervisory staff) Review plan and implementation at least quarterly and complete documentation as required for the support setting (Note: Supervisory staff review includes monitoring of plan implementation and direct service staff documentation.)

4. The role of **other team members,** depends on the member, can include:

   a. Participate in interviews, etc. during the Discovery process to provide information regarding the person's wants and needs as necessary for a particular program,
   b. Attend the planning meeting(s) and participate in the plan development as available,
   c. Communicate with person and team leader/facilitator as needed throughout plan implementation,
   d. Deliver and document services as specified in the plan, and
   e. Attend review meetings.

*Facilitating a Successful Team Meeting/Discussion:*

The team leader/facilitator begins the planning meeting by assisting the person in presenting his or her vision and goals. The vision may be presented in any manner the person desires. The support team then has an opportunity to ask questions and request clarification regarding the person's vision and goals prior to beginning planning to meet the person's vision and goals.

The team leader/facilitator is responsible for facilitating discussion that encourages active participation of all support team members throughout the planning meeting.

1. Some team members may be quiet and may need to be "invited" throughout the meeting to comment or contribute important information.
2. Other team members may get "ahead" of the process or get stuck on a topic. When this occurs, the team leader/facilitator is responsible for bringing the team back into focus on the current topic of discussion and assist in moving forward with planning.

Facilitating discussion may also involve other activities that assist the team in completing the plan, including:

1. Redirecting discussion based upon new information,
2. Restating or summarizing information to assist the team in moving forward,
3. Providing input from professionals who are unable to attend the meeting,
4. Highlighting conflicting information and assisting the team in determining a course of action to address the conflict, and
5. Assisting the person in advocacy efforts regarding his or her interests and needs.

The team leader/facilitator assures that the meeting ends with a full plan which includes actions and strategies related to each outcome or support need identified, designation of responsibility, frequency, target date for completion/review, and method for measuring progress.

*Developing the Plan:*

For each personal outcome/goal, the support team:

1. Identifies strengths that can be used to achieve personal goals:
   a. Strengths, skills and abilities of the person (i.e., specific job skills that assist the person in meeting his or her goals),
   b. Social and community connections of the person and other support team members (i.e., a support team member knows the owner of a local scrapbooking store and a person wishes to take up this hobby; family/friends who can assist with transportation), and
   c. Environmental positives (i.e., lives on a bus route which helps with transportation issues);

2. Identifies challenges or barriers:
   a. Health issues requiring treatment (i.e., diabetes, seizures),
   b. Mental health and behavioral issues requiring intervention/support (i.e., depression, aggression),
   c. Risk factors (i.e., person receives medication placing him or her at risk for a medical condition; person lives in a neighborhood with safety concerns),
   d. Environmental barriers (i.e., person has no reliable means of transportation and lives in a rural area; mismatch between direct service provider's available transportation and preferred frequency of person), and
   e. Other person-specific challenges;

3. Develops strategies to achieve goals and overcome barriers;

4. Identifies known needed treatments/medications (i.e., medication for seizures);

5. Identifies needed assistance/support from others (i.e., need to assist the person in lying down and move furniture/etc. out of the way during a seizure);

6. Identifies skills the person could learn to assist him or herself (i.e., the person may be able to learn improved eating habits to address diabetes);

7. Identifies the available family/friends and other support options previously identified that can assist for each strategy;

8. Identifies opportunities for increased independence to achieve personal goals, including the following examples:
   a. Increasing independence in key daily living areas for a goal of living independently or increased privacy; and
   b. Learning to bank online for someone who wants to budget and acquire some preferred living situation or item.

For each goal/barrier, strategies must be developed including:

1. Specific actions listed in sequence,

2. Who is responsible to assist/support/complete each action,

3. Where the action will take place,

4. What equipment/assistive devices are needed for the action to occur,

5. Frequency of support,

6. How each support will be measured/assessed for completion, and

7. Date for completion or review of each action/support.

No planning meeting or team discussion of an issue should conclude until all items are completed for all identified goals.

### Team Toolkit

If we are to know that we have been successful in implementing solid team processes, we must implement tools/strategies not only evaluate ourselves as a team, but also to hold ourselves accountable to the person and for achieving his or her individual outcomes. This section will provide various tools with instructions that may be implemented to regularly evaluate the team process, progress, as well as assure consistency across teams.

**INTERDISCIPLINARY TEAM REVIEW**

**Based on the above review, team discussion and planning should proceed and address the following:**

**Active Participation:**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| Members interact only when prompted OR the team leader "runs" the meeting. | Some members participate with no prompting, while others require significant prompting. | All members participate; some facilitation by the team leader may be required. | All members participate in discussions and only require minimal prompting for complex issues. | All members openly discuss issues of importance; it is difficult to tell who the team leader is. |

**Focus of Meeting:**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| Meeting is rambling and unclear. | Team correctly identifies issues of concern with facilitation; has trouble staying focused, but returns to area of focus with prompting. | Team stays focused; the meeting may be lengthy; and the team may need prompting. | The team identifies areas of success and concern; stays focused with minimal prompting/ facilitation. | Team efficiently identifies and addresses areas of progress and areas of concern without prompting. |

**Meeting Preparation:**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| The team has not reviewed any information prior to the meeting and/or needed information is unavailable. | Members have reviewed "their" information and/ or information is brought to the meeting for review. | Members have clearly reviewed information prior to the meeting, and areas for discussion have been identified. | Information was reviewed, and recommendations were prepared prior to the meeting. | Information was reviewed prior to the meeting and further assessments, etc. were completed proactively. |

**Goals/Outcomes:**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| Meeting is not begun with a review of life vision or goals (if initial/ annual, no vision/ goals set); objectives/actions are not linked to vision or goals (or barriers to vision and goals). | Goals and life vision exist but are not reviewed; some objectives and actions are linked to the vision or goals while others are not. | Meeting begins with review of the life vision and personal goals; team links objectives and barriers to the goals and life vision with prompting. | Meeting begins with the required review and minimal prompting is needed to link goals and objectives. | Meeting begins with the required review, and the team consistently links all objectives and barriers to the goals and life vision without reminders from the team leader. |

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**Prioritization:**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| Areas of support/ treatment are not identified or prioritized. | Most areas of support/ treatment are identified and prioritized; some may not be. | Areas requiring support/ treatment are identified and prioritized regarding importance to the individual. | Areas requiring support/ treatment are identified and prioritized; ongoing changes made after changes in status. | Areas requiring support/ treatment are identified and prioritized monthly or more frequently as indicated. |

**Planning:**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| The team leaves the meeting with areas identified in need of planning, but no plan is developed. | The team develops an incomplete or inadequate plan. | The team leaves meeting with clear plan to address areas identified; the planning requires facilitation from the team leader to complete the plan. | The planning occurs with facilitation needed only for complex issues or when conflict arises. | The planning occurs spontaneously from the team discussion with no facilitation needed from the team leader. |

**Accountability (Data/Progress):**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| No data available; decisions made are inconsistent with data or with no data (trial/error); plan continues with no modifications in absence of progress. | Team inconsistently uses data to make decisions, and/or modifications are not made timely. | The team uses data to determine progress and need for modifications; where data is not available, a plan is developed to address lack of data. | All areas in #3 are addressed and the team is able to complete review process without facilitation; generalization and maintenance are addressed. | All areas in #4 are addressed; team members anticipate need for further data or modifications when problems are identified prior to the meeting. |

**Rights/Advocacy:**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| Rights are restricted with no justifiable rationale. | Rights restriction are reviewed; plan to fade may be unclear or unsuccessful with no modifications. | Restrictions are used only with due process; plans in place to address fading. | | |

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**Risk Management/Significant Changes in Status:**

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| Significant risk factors/changes in status are missed or not addressed timely. | Significant risks/changes in status are identified; timelines are met, but the issue is not adequately resolved. | Risk Management issues/ significant changes in status are identified and addressed in a timely manner. | Risk issues are proactively addressed; more frequent team meetings occur until the issue is resolved. | #4 is addressed and less significant risks/ changes in status are addressed in between monthly meetings. |

**INDIVIDUAL SUPPORTS REVIEW PROTOCOL**

Please print the name of the Team Leader/Facilitator completing the plan, the date of this review, and the name of the person whose plan is being reviewed.

SUPPORT PLAN COMPLETED BY: _____   REVIEW DATE: _____

PERSON'S PLAN UNDER REVIEW: _____   Agency: _____   Reviewer: _____

For each item, check the appropriate compliance rating using the following guidelines and specifics noted for each item:

3 = THE INFORMATION IS COMPLETE AND CLEARLY CONSISTENT WITH THE PERSON'S INTERESTS AND WISHES; NO RECOMMENDATIONS FOR IMPROVEMENT CAN BE PROVIDED (GOOD BALANCE BETWEEN IMPORTANT TO AND IMPORTANT FOR AS APPLICABLE).

2 = THE INFORMATION IS CONSISTENT WITH THE PERSON'S INTERESTS AND WISHES; RECOMMENDATIONS FOR OTHER CONSIDERATIONS CAN BE PROVIDED BUT DO NOT REPRESENT AREAS OF CLEAR DEVIATION FROM THE PERSON'S INTERESTS AND WISHES OR AREAS OF COMPROMISED HEALTH AND SAFETY.

1 = THE INFORMATION IS NOT IN THE PLAN OR IS INCONSISENT WITH THE PERSON'S INTERESTS AND WISHES OR REPRESENTS A CLEAR POTENTIAL FOR HEALTH AND SAFETY RISKS.

| I. PERSON-CENTERED DISCOVERY AND FUNCTIONAL ASSESSMENT | 3 | 2 | 1 | Comments |
|---|---|---|---|---|
| a. The plan provides a list of things we might admire about the person and is consistent with the following:<br>• Are things we would say about someone else the same age, and<br>• Are not things we would just say about people with disabilities? | | | | |
| b. The plan provides a list of characteristics of people who might best support the person. | | | | |
| c. The plan provides information about the things that are most "important to" the person which reflects things we know from what the person tells us or shows us (with their behavior), not what others think is important. (Note: Consider things like important relationships, activities at home and in the local community, particular places the person may enjoy or like to go, daily routines and rituals, and items that the person likes to have.) | | | | |
| d. The plan provides information about the things that are "important for" the person to remain healthy and safe. (Note: This information should include important health professionals, allergies, special instructions or equipment for the staff with regard to nutritional and mobility needs, and other information those supporting the person should know that may not be specific to health diagnoses and treatment included in the next section.) | | | | |

| | 3 | 2 | 1 | Comments |
|---|---|---|---|---|
| e. The health status section is fully completed.<br>• All current diagnoses or health needs are listed. Current treatment and/or supports needed are noted for each diagnosis.<br>• A description of the person's behavioral concerns and mental health diagnoses is provided if applicable. Current treatment and/or supports needed are noted. (Note: Must be present for all individuals assigned to level 4 or 6 prior to approval.)<br>• Any medical or mental health risks are listed with current treatment and/or supports needed to minimize the identified risks. | | | | |
| f. The plan provides information about how the person communicates best with others and includes information about specific nonverbal/gestures and what they mean to the person. | | | | |
| g. The plan provides information about what is currently working and not working regarding the person's living situation, work/day activities, relationships and supports from the person's perspective and from the perspective of the people who support the person. | | | | |
| **II. PERSONAL OUTCOMES and PLANNING** | **3** | **2** | **1** | **Comments** |
| a. The plan provides a description of "a picture of a life" from the person's perspective and includes where the person would want to live, what the person wants in his/her local community, who the person wants in his/her life, and how the person would spend his/her day. | | | | |
| b. Where appropriate, the plan provides information about things the person has learned or goals he/she has achieved, historical information about the person's medical and mental health/behavioral needs including things tried in the past and what was learned from them. | | | | |
| c. The plan provides a list of prioritized support goals/needs that reflects what matters most to the person (or has the most impact on the person's ability to achieve what matters most to him/her). The plan includes supports needed to maintain relationships and engage in important activities when needed. | | | | |
| d. Support strategies/objectives are clearly linked to achieving the identified goals or removing the barrier.<br>• Steps are sequential and likely to move the person closer to his/her goal or remove the challenge.<br>• Steps/actions specify who will do what to move toward achieving the noted goal/remove the barrier. They are written as action statements.<br>• Steps/actions are included no matter who is the identified as responsible person (i.e., even if family will address). | | | | |

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| | | | |
|---|---|---|---|
| • For personal goals, steps/actions include planning activities needed, steps to accomplish the goal, and guidance regarding needed assistance/prompting for the individual.<br>• Strategies support accessing community resources and support options where appropriate.<br>• For medical/mental health/behavioral concerns, steps/actions address medications and treatments received, lab work needed, doctors/professionals seen, signs/symptoms for staff to observe, and brief statement of response to signs/symptoms. | | | |
| e. Each support strategy has a schedule/target date, method for measuring the progress, and who is responsible. Important people in the person's life are included and represented as natural supports where appropriate. | | | |
| f. Support strategies are functionally linked to increased independence, autonomy, and achievement of desired outcomes (including work and day activities).<br>• Strategies are not focused on ongoing assistance from staff/family or others always doing for the person unless the person is physically unable to learn to perform the task(s) more independently.<br>• Strategies note methods for teaching the individual and increasing his/her ability to do things without waiting or depending on others to do it. | | | |
| g. Support strategies to address each medical diagnosis/health needs (including health risks) are noted and include consultations with needed professionals and any medication/treatments along with specific instructions for those supporting the individual. Strategies include:<br>• Doctor to be seen,<br>• Supports needed to see doctor,<br>• Medications taken for condition (doses do not have to be specified),<br>• Symptoms that staff should look for related to each medical/health condition,<br>• Expected staff response to symptom presentation,<br>• Any ongoing supports needed for symptoms (not common), and<br>• Teaching strategies to develop independence in managing condition if appropriate. | | | |
| h. For individuals with mental health/behavioral challenge strategies the following are included:<br>• Doctor to be seen,<br>• Supports needed to see doctor,<br>• Medications taken for condition (doses do not have to be specified), | | | |

| | | | |
|---|---|---|---|
| • Symptoms that staff should look for or early cues and prevention for behavioral challenges,<br>• Expected staff response to symptom presentation or behavioral challenge,<br>• Any ongoing supports needed for symptoms (not common), and<br>• Teaching strategies to develop replacement or coping skills.<br>(NOTE: If the person needs a behavioral plan, it is attached, and it addresses all the behavioral challenges with prevention, intervention, and teaching strategies.) | | | |
| i. A schedule is completed for each person based upon the Personal Outcomes section. The schedule reflects employment, transportation, school, shared support hours, routine support hours, and any other relevant supports provided. | | | |
| j. An alternate schedule is completed for holidays, weekends, vacations, etc. The schedule does not just reflect unanticipated prn or "emergency" hours. | | | |

| PROCESS SCORING | | | | |
|---|---|---|---|---|
| **SCORING** | **SCORE TOTAL** | **÷** | **TOTAL** | **PERCENT** |
| NUMBER OF ITEMS SCORED "1" | | ÷ | 17 | |
| NUMBER OF ITEMS SCORED "2" | | ÷ | 17 | |
| NUMBER OF ITEMS SCORED "3" | | ÷ | 17 | |
| PLAN APPROVAL DETERMINATION (check the one that applies):<br>Approved with no recommendations: __<br>    (NOTE: Should only be checked if all items are rated "3.")<br>Approved with recommendations: __<br>    (NOTE: Recommendations should be considered at the first quarterly review for any item rated "2.")<br>Not approved: __<br>    (NOTE: Must be checked if any items are rated "1.") | | | | |

**BEHAVIORAL HEALTH AND SUPPORT NEEDS**

Since the 1960s, it has been widely accepted that people with developmental disabilities can and do experience co-occurring behavioral health conditions and challenges. It is estimated that about 40% of individuals with intellectual/developmental disabilities have a co-occurring mental health diagnosis while an additional group of individuals may also present with behavioral challenges (with the addition of this group the percentage may increase up to 70%). The behavioral presentation of any person may be influenced by many factors including the following:

1. Challenges in self-determination or a mismatch between person-centered desires/goals and the person's current supports and living situation,
2. Presence of or exposure to trauma,
3. Presence and status of underlying medical conditions,
4. Presence and status of co-occurring mental health conditions, and/or
5. Learned behaviors and environmental/contextual factors.

A thorough assessment of any individual presenting with "behavioral" needs is essential prior to development and implementation of any supports or treatment. A comprehensive assessment must address the areas noted above in the hierarchical order noted here.

A true Positive Behavior Supports Approach does **NOT** necessarily involve the completion of a formal functional assessment and development of a formal behavior support plan. Rather, it begins with a focus on the broader person-centered and self-determination aspects of a person's plan; is sensitive to and aware of the possibility of trauma for each person supported; refers for any needed additional professional assessments to evaluate for and provide treatment related to any medical or mental health needs; and THEN looks at formal environmental and functional assessments to develop a behavioral support plan.

Important person-centered thinking considerations should always be the first area explored for any individual presenting with behavioral challenges. These areas can get overlooked or may experience drift when a person receives a large amount of support from others. Reference back to earlier sections of this handbook may be useful for any individual experiencing these types of challenges. The following overview can be used for consideration by any team when a person is presenting with behavioral challenges that are emerging, increasing slightly, or not improving.

# Support Team Person-Centered Guide

Non-negotiables
- ❑ Non-negotiables are identified and listed in the plan.
- ❑ Non-negotiables are available/accessible/happening routinely.

Important Routines and Rituals
- ❑ Important routines and rituals are identified and listed in the plan.
- ❑ Important routines and rituals are happening consistently.

Relationships
- ❑ Important family/friends are identified and listed in the plan.
- ❑ Visits/Calls/Contacts are occurring as listed in the plan.

Work/School
- ❑ Important preferences/non-negotiables/routines are in place.
- ❑ Preferred work activities/schedule are identified and listed in plan.
- ❑ Preferred work activities/schedule are available/accessed routinely.

Preferred Activities/Interests
- ❑ Preferred activities/interests are identified and listed in the plan.
- ❑ Preferred activities/interests are available/accessed/happening routinely.

Major Life Changes
- ❑ Illness of family/friend
- ❑ Death of family/friend
- ❑ Move of family/friend
- ❑ Personal move/change in living situation
- ❑ Family birth/wedding/addition
- ❑ Family divorce or other change
- ❑ Change in work/school
- ❑ Change in staff/support
- ❑ Major holiday

Environmental Issues
- ❑ Consistently occurs at sometimes of day but not others.
- ❑ Consistently occurs on some days of the week but not others.
- ❑ Consistently occurs with some people but not others.
- ❑ Consistently occurs during some activities/situations but not others.
- ❑ Occurs differently in crowded situations than non-crowded.
- ❑ Occurs differently in noisy situations than non-noisy.

Other Issues/Concerns
- ❑ Review of plan reveals vision/goals/preferences that pass the "like you and me" test.
- ❑ Other significant issues/questions identified following review.

**Understanding Trauma and Trauma Informed Supports**

Individuals with developmental disabilities experience trauma at much higher rates than is typical for individuals without disabilities. Rates across studies of sexual abuse range from 25-49% along with higher rates for other forms of abuse and a higher likelihood of being a victim of a crime. In all, research suggests that 60-90% experience some form of trauma with more than 90% of victims reporting they were abused on multiple occasions (57% noted more than 20 occasions and 46% said too often to count). Of those who were noted to be victims of abuse/trauma, 65.4% who were victims did not receive counseling or therapy.

It is important to recognize as a system that trauma for individuals with intellectual/ developmental disabilities is occurring at tremendous rates and that there is a need to build consistency across agencies/ service systems via a uniform approach. Any agency supporting individuals with intellectual/developmental disabilities must be aware of possible risk of or exposure to trauma. Understanding of each person's risk and history of exposure to trauma is important in all aspects of supporting the person and must include efforts to avoid re-traumatization.

A guide for assessing possible risk and/or exposure to trauma follows and is recommended as a general best practice. The information gathered in that tool should then be used by the support team to determine modifications in support for the person and/or need for further assessment. It may be that the team will need the assistance and guidance of a mental health professional depending upon the nature and severity of the risks and/or previous exposure.

To be more trauma informed, agencies and their staff should consider the following in supporting all individuals:

1. Showing the person respect and dignity;
2. Helping the person to feel safe and valued;
3. Instead of telling the person what he or she should do or needs to do, giving choices;
4. Before behavior escalates, considering that the person is beginning to see him or herself as being in danger and helping him or her feel safe, comforted, and grounded BEFORE becoming a danger to self/others;
5. Honoring the person's right to have control; and
6. Moving from a focus on "what's wrong with the person" to one of "what happened to the person and how does what happened to him or her affect his or her behavior."

Additional guidelines and best practices related to trauma informed support and trauma related treatment are available via more intensive technical assistance.

*Review and indicate any of the following the individual has experienced. For any are checked, provide (in assessment) a brief description including details of trauma, date, any attempts to adjust supports (based on adverse childhood experiences identification from CDC and SAMHSA with supported modifications and additions based upon trauma-informed approaches for persons with intellectual disabilities).*

- ☐ Physical Abuse
- ☐ Sexual Abuse
- ☐ Emotional Abuse
- ☐ Physical Neglect
- ☐ Emotional Neglect
- ☐ Social trauma (e.g., rejection, teasing, bullying, name-calling, verbal abuse)
- ☐ Violence in the home
- ☐ Substance use/abuse in home
- ☐ Mental Illness in home
- ☐ Parental separation or divorce (or death of a parent in childhood)
- ☐ History of multiple or failed foster-care placements
- ☐ Loss, death, staff turnover
- ☐ Family member (in home) in jail
- ☐ History of institutionalization/incarceration
- ☐ History of restraint or significant restrictions used in support plan(s)

*Review and indicate any of the following which may be currently present for the individual. For any checked, provide (in assessment) a brief description of situation and any current supports in place to mitigate risk.*

- ☐ Individual lives in community with ready access to substance use
- ☐ Individual lives in an area in which violence if prevalent
- ☐ Lack of **needed** support/supervision (could also be limited number of people providing support)
- ☐ Lack of **needed** parental involvement (at school, community, etc.)
- ☐ Limited or no social support network
- ☐ Limited or no friends
- ☐ Limited individual or family financial resources
- ☐ Limited or no job opportunities
- ☐ Individual reports feeling unsafe in his/her home or neighborhood
- ☐ Family/staff report high levels of stress/frustration

*Review and determine if any of the following are present in the person's community and if so are being accessed.*

- ☐ After school programs
- ☐ Church/faith-based programs
- ☐ Education/job training programs
- ☐ Other community resources that support positive school/work/community outcomes
- ☐ Access to needed training for any family/staff support
- ☐ Access to respite supports when individual needs sustained support throughout day/night

**Behavioral Health: Towards Recovery and Resiliency**

The nationally recognized definition of recovery is:

"A process of change through which individuals improve their health and wellness, live self-directed lives, and strive to reach their full potential"

For agency's providing support and treatment to individuals with developmental disabilities, this is very consistent with the goals of person-centered thinking as a broad context and as such should be readily adapted into each agency's approach to behavioral health treatment.

It is important to remember that for a person to experience recovery, a comprehensive mental health evaluation paired with appropriate treatment based upon the evaluation is essential. Every person who presents with behavioral symptoms will not improve with provision of what is considered more traditional positive behavior supports and a behavior support plan. Some individuals will need therapeutic interventions along with appropriate medications. People with disabilities can and do benefit from accessing more traditional mental health therapy including the following to name a few:

1. Cognitive Behavior Therapy
2. Dialectical Behavior Therapy
3. Multi-systemic Therapy
4. Solution Focused Therapy

Appropriate therapy and skills building within the therapeutic context assist in symptom resolution, recovery and eventually resilience.

For individuals with developmental disabilities, building resilience may need to be a more well thought out and focused part of the therapeutic approach. Important resilience factors to remember include:

1. Caring and Supportive Relationships
2. Positive Sense of Self
3. Skills in communication
4. Capacity to make realistic plans and carry them out
5. Skills in problem solving
6. Capacity to manage strong feelings and impulses

More specific assistance, including best practices and tools related to mental health treatment, recovery and resiliency, is available via more intensive technical assistance.

**Positive Behavior Supports: Supporting People with Complex Needs**

The primary focus of Positive Behavior Supports is:

Helping people reach their vision of a best life by supporting them to develop and use healthy, socially desirable behaviors and overcome behaviors that are destructive and stigmatizing.

As noted previously, a true Positive Behavior Supports Approach must have already considered the previous areas within this section on Behavioral Health Needs.

Consistent with a focus on person-centered approaches, Positive Behavior Supports continue to push the support system to move from *treating others the way you would want to be treated* to ***treating others the way they want to be treated.***

It is essential to remember that everyone is different, and everyone has strengths as well as challenges. All behaviors and symptoms present occur within a context, and effective support and professional treatment (when needed) must come from and be embedded within the person-centered plan for each individual.

Consideration of which support approach to take and/or needed additional referrals or consultation should follow the guidance noted below:

| Support Team | Medical Consult | Psychiatry Consult | Psychology/ Behavioral Health Consult | Emergency Help |
|---|---|---|---|---|
| 1. Known recent life changes<br>2. Presentation is different across situations<br>3. Very low level of danger | 1. New behavior (never seen)<br>2. Sudden worsening<br>3. Known historical or family connection<br>4. Suspected/ known genetic condition<br>5. Signs/ symptoms of illness | 1. Known mental health condition with medications<br>2. Other odd behavior accompanies behavior<br>3. May need physician's emergency certificate (PEC) | 1. Behavior is dangerous<br>2. Efforts to troubleshoot simple solutions do not work<br>3. Medical issue not likely/RO<br>4. Known mental health condition<br>5. Prior problem needing intervention of a professional | 1. Imminent danger to self<br>2. Imminent danger to others<br>3. Major change in awareness or alertness |

Additional tips/guidelines are available in this section for evaluating when an underlying medical issue may be present; these are important considerations given the often co-occurring medical diagnosis many individuals with developmental disabilities may experience. A later section of this handbook will provide more detail related to general health conditions and supporting health and wellness. The following are common medical conditions often found to be associated with behavioral presentations that may otherwise be identified as behavioral challenges:

*Conditions that may be associated with pain/discomfort:*

- GI Issues (Gastro Intestinal Issues)
- UTIs (Urinary Tract Infections)
- Ear infections
- Dental Pain/TMJ (Temporomandibular joint) Syndrome
- Constipation/Diarrhea
- Hemorrhoids
- Disc pain (back)
- Kidney Stones
- Arthritis/joint pain
- GYN (Gynecology) issues (yeast infections; polycystic ovary disease)
- Allergies (non-seasonal)
- Skin conditions
- Headache/migraine

*Medical Conditions that may be associated with Cyclical Changes:*

- Menstrual pain
- Seasonal allergies
- Fluctuating endocrine problems (hyper or hypothyroidism)
- Sensitivities to changes in the weather

*Medication Related Considerations:*

- Changes in existing medications
- Activating medications (decongestants)
- Psychotropic side effects (akathisia and related issues)
- Medication side effects that create other existing medical conditions (e.g., nausea, headache, etc.)

*Other Known Medical Issues:*

- Changes in blood sugar associated with diabetes
- Seizure activity
- Changes in Blood Pressure
- Muscle spasms
- Discomfort associated with wheelchair, clothing, furniture
- Nicotine/caffeine withdrawal
- Episodic sleep disturbance

Support Team's may also engage in active problem-solving efforts to look for simple environmental impacts on behavioral challenges. When a behavioral health professional is already actively engaged, he/she must be a part of this process and/or the team should bring any information or data from its efforts to him/her. When a behavioral health professional has not been actively engaged and the behavior is not inherently risky/dangerous, these tips and guidelines may assist a support team in identifying some obvious possible considerations that can be adjusted for the person. These guidelines are also included this section of the handbook.

Finally, if a person's behavioral challenges cannot be addressed via the person-centered efforts, are not resolved by considering any needed medical impacts and treatment, and cannot be addressed with appropriate mental health treatment for any trauma related needs or co-occurring mental health diagnoses, then the person will need a formal functional behavioral assessment and may need a formal behavior support plan. Consider the need for a formal functional behavior assessment when:

1. Significant health/safety risk to person/others exists.
2. Challenging behavior significantly interferes with quality of life, and other efforts have not been successful.
3. Team spends more time focusing on restrictions or rights of person/others are compromised.
4. Current living situation is at risk.
5. Current behaviors are increasing in intensity/severity and no identified drift in supports/treatment is occurring, and other involved professionals have been consulted to rule out other impacts.

When a formal functional behavioral assessment is needed the following guidelines should be followed:

1. Person-centered information must be addressed and included.
2. Description of behavior(s) must be measurable and observable.
3. Meaning must be considered: what behavior would say if it could talk.
4. Communication, medical, psychiatric, environmental, other factors (e.g., trauma) that impact behavior must be evaluated.
5. Context must be evaluated: where, when, with whom, during what activity does it occur.
6. Maintenance of the behavior must be identified: what person gets or avoids.
7. Skills must be identified: what healthy behaviors person has and can also learn to replace problem behavior.

If the functional behavioral assessment determines that a formal behavior support plan is needed, the following guidelines must be present consistent with best practices:

1. Behavior Support Plan maintains person-centered approach: honors choice and preference – there is no cookbook approach.
2. Behaviors are described clearly: observable and measurable.

3. Plan must be practical and doable.
4. Antecedents and consequences are identified.
5. Functional skills building is incorporated and reflects person's choices, goals, independence, and opportunity to have meaningful activities/relationships: type/method of training is geared to person's needs.
6. The Plan supports positive, healthy, safe, educational environment based on person's preferences and needs.
7. The Plan aims to eliminate conflicts surrounding choice: no choice = no control = anger = challenging behavior.
8. Positive, healthy, and meaningful social interactions with staff and <u>others</u> are readily available (reduce interactions that contribute to challenging behavior).
9. Plan includes guidance on asking for help as problems surface.
10. Data collection method should be specified and consistent across staff.

Additional tools related to supporting individuals with behavioral health needs and challenges can be provided following a more intensive technical assistance activity.

## Support Team Guide for Recognizing Signs of Pain/Illness for Individuals Exhibiting Behavioral Challenges

Communication
- ❑ Verbal reports of pain/discomfort.
- ❑ Use of known indicators of pain/discomfort.
- ❑ Person is moaning/groaning/crying.

Sudden Onset of Behavioral Challenges
- ❑ Self-injury begins and is directed to particular part of the body.
- ❑ Aggression/Property Destruction begins and is paired with clear signs of irritability/crying/moaning.
- ❑ Inappropriate sexual behavior begins when it has never presented previously.
- ❑ Changes have occurred in clothing, soap, detergent or other possible skin irritant.
- ❑ Recent diet changes OR not following required dietary guidelines related to medical symptoms.
- ❑ New behavior occurs, and person has one of the known medical conditions associated with pain/discomfort.

Abrupt Changes in Existing Behavioral Challenges
- ❑ Changes in what behavior looks like.
- ❑ Change in intensity of behavior.
- ❑ Changes have occurred in clothing, soap, detergent or other possible skin irritant.
- ❑ Recent diet changes OR not following required dietary guidelines related to medical symptoms.
- ❑ New behavior occurs, and person has one of the known medical conditions associated with pain/discomfort.

Cyclical Behavioral Patterns
- ❑ If female, pattern seems associated with menstrual cycle.
- ❑ Person has diabetes and blood sugar fluctuations occur.
- ❑ Behavior occurs in seasonal cycle.
- ❑ Behavior varies with sleep changes.
- ❑ Person has diagnosed condition that could have cyclical changes. [NOTE: Nurse involvement may be needed.]

Known GI related Illness
- ❑ Behavior increases (intensity or duration) surrounding mealtimes.
- ❑ Behavior involves a form of hand mouthing/biting.
- ❑ Family history of significant pain/discomfort with same/similar condition.

Known GYN related illness
- ❑ Behavior involves what appears to be "inappropriate" touching of oneself.
- ❑ Inappropriate sexual behavior while not cyclical does come and go and may be missing for significant periods of time.
- ❑ Family history of significant pain/discomfort with same/similar condition.

Known Medical Condition associated with Pain/Discomfort [NOTE: If present and behavioral issue recently started or increased, involvement of nurse consultant if available may assist in evaluating these issues.]

- ❑ Migraines.
- ❑ History of recurrent Infections (UTIs/Ear infections).
- ❑ Known back/joint conditions.
- ❑ Known allergies.
- ❑ Existing skin condition.
- ❑ Seizure Activity.
- ❑ Family history of significant pain/discomfort with same/similar condition.

Medication

- ❑ Recently started medication or medication prescribed to treat temporary condition.
- ❑ Recent Medication Change.

Mobility/Positioning

- ❑ Person uses customized wheelchair for mobility/support and some time has passed since last evaluation.
- ❑ Person has condition associated with contractures or other physical need that may impact comfort but does not currently have/use customized wheelchair.
- ❑ Person requires repositioning assistance and some time has passed since last evaluation OR person does not at this time have equipment to assist/support needed repositioning.

**Support Team Active Problem-Solving Guide**

1) Is the behavior occurring at certain times of day?
   a. What is happening during these times that is not happening at other times?

   b. What is not happening during these times that is happening at other times?

   c. What type of day/schedule does the individual typically like?

   d. What times of day are best for the person? What is different about these times than others, particularly those that are most problematic?

2) Is the behavior occurring on certain days of the week?
   a. What is happening on these days that is not happening on other days?

   b. What is not happening on these days that is happening on other days?

   c. What days are usually best for the person? What is different about these days than others?

   d. How was the bad day different from a typical day?

3) Is the behavior occurring with certain people?
   a. What are these people doing that other people are not doing?

   b. What are these people not doing that other people are doing?

   c. Does the person have a history of problems with this staff member?

   d. Who does the person really like/have good days with? What is different about what this individual is doing?

4) Is the behavior occurring during certain activities?
   a. What is happening during these activities that is not happening during other activities?

   b. What is not happening during these activities that is happening during other activities?

   c. Has the person typically not liked these activities?

   d. What kinds of activities does the person like?

5) Are there other environmental/structural concerns that impact this person?

   a. crowds

   b. noise level

   c. structure/routine

   d. changes/other

LOUISIANA
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HEALTH

If we are to help people to have better lives and achieve their overall vision and goals, we must consider each person's general health support needs. This begins not only with promoting preventive health and wellness, but also with recognizing common signs and symptoms of illness. Often for the people we support, health issues can get in the way of overall quality of life areas such as participating in the community, building relationships, being employed, being engaged in meaningful activities of their choosing, and overall independence. In this section, we will focus on tips and guidelines not only for promoting preventive health and wellness, but also effective ways to document what is being observed on an individual basis.

## Promoting Preventive Health and Wellness

Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.

There are eight dimensions of wellness: occupational, emotional, spiritual, environmental, financial, **physical**, social, and intellectual. Each dimension of wellness is interrelated with another. Each dimension is equally vital in the pursuit of optimum health. One can reach an optimal level of wellness by understanding how to maintain and optimize each of the dimensions of wellness.

In this section, we will discuss Physical wellness: Physical wellness relates to maintaining a healthy body and seeking care when needed. Physical health is attained through exercise, eating well, getting enough sleep and paying attention to the signs of illness and getting help when needed.

Through significant advances in healthcare, particularly intensive care for newborns, early diagnosis and treatment, as well as improvements in chronic care and preventative health care management, 65%-90% of children diagnosed with cerebral palsy survive. More than 90% of individuals with cerebral palsy who have mild to moderate impairment have a survival rate that is very close to individuals who have no health disparity. People with other development disabilities, such as spina bifida, epilepsy and Down syndrome, also appear to be leading longer, healthier and more productive lives.

Motor impairments (e.g., difficulty with movement and posture) and other associated medical conditions in individuals with disabilities may speed up the "typical" aging process. "Typical" aging is usually accompanied by a high rate of medical and functional problems (e.g., arthritis, heart disease, etc.) after age 70. However, in some individuals with a disability, an "aging gap" develops and they begin to show higher rates of medical and functional problems at age 50 or younger, 20 or more years earlier than the portion of the population that does not have disabilities.

It is not entirely clear what causes this "aging gap." However, it is very clear that because of the potential for earlier development of these chronic and often debilitating health problems in

people with disabilities, it is critically important for health care providers, individuals with disabilities, their families, and care givers to make sure that people with disabilities receive the appropriate medical and preventative health care and other environmental supports they require throughout their lifespan so that they may focus on maximizing their abilities as they age.

Basic preventative health care recommendations (i.e., exercise, healthy diet, smoking cessation and good oral health), as well as preventative health screenings, should be an integral part of the overall health care plan for all individuals. However, it is a particularly important component of the overall health care plan for people with disabilities.

The greatest advantage of preventative health screening is identifying and detecting problems early in an attempt to avoid serious illness and prevent further functional deterioration. If we focus our efforts on excellent general wellness programs and preventative medical care, as well as early recognition of potential disease conditions by identifying signs and symptoms that must be reported immediately, the individuals we support will continue to benefit from advances in healthcare and enjoy the healthy and independent lives they deserve as they age.

**<u>Recognizing Signs and Symptoms of Illness</u>**

**Recognizing Changes:**

‣ <u>Early identification of change in a person can save his or her life.</u>
‣ You get to know a person by spending time with him or her and learning what is usual for him or her.
‣ If you do not know what is normal for a person, you will not know when something has changed.
‣ You need to know a person's health history.

**Key Words:**

‣ *Medical Emergency*: An unexpected illness or injury calling for immediate attention to address a threat to a person's life or safety.
‣ *Routine Treatment*: Applying simple First Aid or following doctor's orders in response to signs of injury or illness.
‣ *Seizure*: An abnormal electrical discharge in the brain.
‣ *Signs and Symptoms*: Evidence of a disease, illness or injury as observed by the direct service worker or reported by the person.
‣ *Urgent Call to Doctor*: An urgent call to the person's doctor to report potentially serious signs or symptoms of illness or injury.

**What are we looking for?**

‣ Lung problems, cough with sputum, chest pain, breathing problems, fever (Aspiration and or Aspiration Pneumonia)

- Breathlessness, wheezing or any breathing difficulties
- Chest pain
- Chest pain with breathlessness, cough
- Bleeding from the rectum, blood in stool, pain
- Abnormal vaginal bleeding
- Convulsions / Seizures
- Abnormal discharge from vagina or penis
- Ear problems, pain, discharge, ringing in ears, deafness, dizziness
- Gastrointestinal problems: vomiting, diarrhea, pain, fever
- Headache with other symptoms such as nausea, vomiting, vision disturbances
- Inflammation of Eyes or eyelids: red eyes, itching, pain, discharge
- Flu like symptoms: headache, chills, fever, pain, sore throat
- Kidney symptoms: pain in lower back, fever, blood or pus in urine, vomiting, headache, fatigue
- Symptoms of liver problems: yellow skin, fatigue, dark urine, itching skin
- Sudden or severe abdominal pain, skin lesions or ulcers
- Skin rash
- Severe sore throat, hoarseness, voice changes
- Excessive thirst
- Vision problems that are reported as new problem
- Urinary track problems: urinary frequency, pain on passing urine, blood in urine

**Observation and Communication:**

*Observation* means using all of your senses: sight, hearing, touch and smell.
- You can see a physical change, such as a tear-streaked face, redness or swelling of the skin or cloudy urine.
- You may hear noisy breathing, crying, moaning, coughing or screaming.
- You may feel hot, moist or cold skin; you may smell an unusual or unpleasant odor coming from the individual's mouth, body or body fluids.

*Communication* includes both asking questions of and listening to the individual and others. A good direct service worker acts like a detective… and asks a lot of questions. If a person tells you that her stomach hurts, you might ask "When did it start hurting"?

Or…

"Can you show me where it hurts?" You may see the individual holding her stomach, grimacing and crying, you might ask, "Does your stomach hurt?"

If the person is unable to use words to tell you, your detective skills - observation, listening and questioning - becomes even more important. A good listener "hears" both words and other ways of communication, including behavior.

**Assessing What to Do When You Learn About a Change:**

▶ Many if not most changes in a person's daily routine, behavior, way of communicating, appearance, manner or mood, and/or physical health, require the direct service worker to TAKE ACTION.

▶ After the direct service worker has identified a change, he or she must <u>assess</u> whether the change is a potential sign or symptom of illness or injury and decide the appropriate level of response required. <u>Contact Supervisor always when you identify a change.</u>

**Levels of Emergency Response:**

Medical emergencies that require immediate medical attention (**calling 911**):

**ALWAYS CALL 911 if the person:**

▶ Has bleeding that cannot be controlled

▶ Is or becomes unconscious not related to a seizure

▶ Has no pulse

▶ Has trouble breathing or is breathing in a strange way

▶ Has chest pain or pressure in chest

▶ Has severe injuries such as a broken bone as in a result of an accident

▶ Is choking (not breathing and not coughing)

▶ Has injuries to the head, neck or back

▶ Has a seizure lasting five minutes or has a continuous seizure

▶ Has suffered electrical shock

▶ Is drowning or near drowning

▶ Experiences paralysis, numbness or increased confusion

▶ Suffers severe burns (i.e., burns that cover more than one part of the body or is on the head, neck, hands, feet, or genitals)

▶ Has been poisoned, or you think he/she has been poisoned (depending on policy you may need to call poison control)

**Urgent Call to Doctor:**

An urgent call to a doctor is prompted by potentially serious signs or symptoms that require a timely report to the person's doctor.

The following are examples of changes that may be signs and symptoms of illness or injury that require an urgent call to the doctor:

▶ Rapid change in behavior or an increase in challenging behavior such as aggression or self-injurious behavior (SIB)

▶ Sleeping most of the day; unusual difficulty arousing; unusual fatigue

▶ Scratching or holding one or both ears

- Holding abdomen
- Dramatic change in facial expression or demeanor
- Evidence of pain or discomfort that is not easily explained
- New or sudden onset of incontinence
- Onset of fever of 101 degrees or higher
- Diarrhea or vomiting lasting more than four hours
- Rash, lasting several days or getting worse
- Increase in seizure activity
- Onset of limping, inability to walk, or difficulty in movement
- Severe sore throat/difficulty swallowing
- Infection at injury site
- Swelling of any part or multiple parts of the body

**Routine Treatment:**

Signs or symptoms that may be addressed with Simple First Aid or for which there is a written doctor's orders can be treated in the home.

Example: A direct service worker may provide minor First Aid in the home for a small scratch on the finger. Some symptoms reported by the person, such as headache or swelling of the ankles, may be treated in the home if there are written doctor's orders that specify what to do.

**NOTE: The Direct Service Worker must always be familiar with the individual, his or her health history, medications, and any written doctor's orders before deciding what to do.**

**Reporting and Documenting Changes:**

Regardless of what action you (as the direct service worker or administrator) take, you must report (tell it) and document (write about it) in some way.

- Medical emergencies must be documented in the person's record.
- All calls to the doctor must be documented in the person's record.
- Any treatment provided in accordance with a written doctor's order or simple First Aid must also be documented in the person's record.

**Reporting and Documenting Guidelines:**

- Write down what the person **said or did** to communicate the change. (Example: Bill said, "My stomach hurts." or "Fred walked up to me and pointed to his stomach, frowning and moaning.")
- **Do not** try to make a diagnosis. The direct service worker is not a health care professional, he or she is to describe the changes only.

- **Do not** document your **personal** opinion. (Example: "Bill said his arm hurt, but I do not think there is anything wrong.")
- **Be specific** when reporting and documenting observed changes. (Example: "I heard Jane screaming; she was sitting on the sofa in the living room. The screaming lasted for about two minutes.")
- Signs or symptoms of changes reported to others (i.e., doctors, dentists, the service coordinator, supervisor, and nurse) must also be documented.
- Documenting changes you have identified is important because many changes occur slowly over time and will only be identified if you consistently document and share your observations.
- Signs and symptoms may be an indication of possible abuse or neglect which you are mandated to report to the appropriate protective service agency.

**Managing Chronic Health Care Conditions:**

- We have discussed in the basics of identifying general health changes and, in Signs and Symptoms of Illness or Injury, the need to have action taken and to report your observations and actions.

It is impossible to review the proper care and management guidelines in one training for all chronic health conditions that the direct service worker or administrator will encounter. We highly recommend that you discuss with your supervisor, health care contractor or nurse, the specific protocols and health care guidelines that you will need further training.

Each person is unique and care plans can be very different for individuals with the same chronic health condition.

**High Risk Health Problems:**

- Aspiration Pneumonia
- Diabetes
- Epilepsy or Seizure Disorders
- Cerebral Palsy
- Skin Breakdown
- Constipation
- Choking / Dysphagia
- Sun and Heat related illness
- Age Related Health Conditions
- Poor Oral Health
- Health Problems Associated with Aging

▸ **Of Vital Importance**: All individuals who spend more than <u>6 hours</u> a day in a bed or wheelchair or who are immobile in any fashion have a 70% chance of developing Aspiration Pneumonia or some type of skin breakdown.

**ALWAYS BE AWARE OF THESE POSSIBILITIES AND IMMEDIATELY REPORT ANY SUSPICIONS TO YOUR SUPERVISOR AND/OR PHYSICIAN/NURSE**.

**Remember, it is you, the direct service worker, who will notice any of these signs and symptoms first; that means you are the first person who can possibly prevent a life-threatening condition**.

**YOU MUST REPORT (tell someone) AND RECORD (document) YOUR ACTIONS AND THE ACTIONS OF OTHERS**.

*<u>Common Medical Problems seen in People with Developmental Disabilities:</u>*

❖ **ASPIRATION PNEUMONIA**

**What is Aspiration?**

*Breathing any foreign matter or substance into the lungs.*

▸ Aspiration occurs when food or fluid enters the airway (lungs). Food or fluid can be aspirated either on the way down to the stomach or on the way up, such as when vomiting.
▸ When aspiration occurs, the lungs recognize the food/fluid as foreign material.
▸ Gagging and coughing is a normal response and if the material is coughed out, little or no airway damage occurs.

**What to do for Choking:**

*Choking is a blockage of the airway, usually caused by a piece of solid food.*

▸ If the material cannot be dislodged, it can set up a chemical reaction that may lead to pneumonia and even death.
▸ The person may not be unable to cough, talk or even breathe depending on how much of the airway is blocked.
▸ Choking should cause an immediate response from caregivers - an urgent intervention, such as a call to 911 if the blockage cannot be dislodged or a follow-up call to the physician reporting the incident if the blockage has dislodged.

**Reasons for Aspiration:**

▸ Uncoordinated swallowing muscles or weakened cough/gag reflexes because of conditions affecting the nerves, such as a stroke, Parkinson's disease or dysphasia.

- Poor body alignment - person not able to sit upright when eating. (If person must eat or be fed in bed make sure the head of the bed is raised to at least a 30-degree angle. The person should remain in that position for 45 minutes after eating.)
- Poor chewing ability, due to missing or loose teeth, teeth in poor repair, or poorly fitting crowns, bridges or dentures.
- Gastro esophageal reflux disease (heart burn), which causes stomach contents to flow back into the throat (esophagus).
- Taking medications that make a person drowsy or having a medical condition that causes fatigue and weakens the gag and swallowing reflexes.
- Being fed by caregivers, who may not be familiar with feeding the person and who may feed him/her too rapidly or put too much food in his/her mouth at one time making swallowing difficult.
- Having decreased lung capacity and lung disease due to chronic respiratory illnesses. (These diseases make a person more susceptible to pneumonia.)
- Using a feeding tube - A person who requires use of a feeding tube for nourishment is at high risk; the person <u>must be fed</u> in an upright sitting position and remain in an upright position for 45 minutes after meal just <u>as if he/she was eating orally.</u>

**What is Aspiration Pneumonia?**

- Inflammation of the lungs and airways to the lungs (bronchial tubes) from breathing in foreign material - usually food, liquids, vomit or fluids from the mouth into the lungs. This may lead to a collection of pus in the lungs, an inflammatory reaction, and lung infection – **<u>PNEUMONIA.</u>**

**Signs and Symptoms of Aspiration Pneumonia:**

- Bluish discoloration of the skin caused by lack of oxygen
- Chest pain
- Cough (could have foul-smelling sputum, or sputum containing pus or blood, or greenish sputum)
- Fatigue
- Fever
- Shortness of breath
- Wheezing
- Breath odor
- Excessive sweating
- Swallowing difficulty

**Complications of Aspiration Pneumonia:**

- Acute respiratory distress syndrome
- Low blood pressure

- ▸ Pneumonia with <u>lung abscess</u>
- ▸ Shock
- ▸ Spread of infection to the bloodstream (bacteremia – sepsis)
- ▸ Spread of infection to other areas of the body
- ▸ Possible death

**Prevention of Aspiration:**

- ▸ Feed small amounts.
- ▸ Put food on one's unaffected strong side if possible.
- ▸ Allow a 30-minute rest period before meals.
- ▸ Avoid feeding if person appears to be heavily sedated.
- ▸ Select thickened liquids such as nectars, instant breakfast drinks **if ordered.**
- ▸ Provide oral care before and after meals and more frequently if needed.
- ▸ In children and infants, make sure small objects are not placed in the mouth.
- ▸ Always follow Physical Support for Positioning during meal time, as in elevating head of bed, placing pillows, or sitting person up in chair if they are able.
- ▸ Make sure after meals that the person stays up for at least 45 minutes before laying head down; this applies even to those who use feeding tubes

**What to do if you suspect Aspiration:**

- ▸ You must <u>ALWAYS document what you see, hear, smell or are told by the person or family member in the progress notes.</u>
- ▸ You must communicate a potential problem to your supervisor, also <u>document in your notes what your supervisor said</u>. The supervisor will report to the RN, or the agency nurse consultant. The Nurse will communicate with the physician.
- ▸ You must follow up – what was said or done must also be documented. This follow-up may take a period of day or longer; it is still your responsibility to document what actions were taken and what the outcome of your reporting was. Did the person get better, are there new orders, did the person go to the hospital? What happened as a result of your reporting a potential problem?
- ▸ Of course, as always, if the person is having difficulty breathing, turning blue, gasping for air, it then becomes a medical emergency and you must **first call 911.**

Aspiration as you can see in most cases is preventable, and therefore, very important to watch for in community settings.

Aspiration and the complication of aspiration pneumonia are one of the leading causes of preventable conditions that can lead to the <u>premature death</u> of a person with a developmental disability.

❖ **PRESSURE SORE/ BEDSORE = DECUBITUS ULCER**

**What are Pressure Sores?**

▸ Pressure sores can occur when a person is bedridden, unconscious, unable to sense pain, or immobile.

▸ Pressure sores are ulcers that occur on areas of the skin that are under pressure from lying in bed, sitting in a wheel chair, and/or wearing a cast for a prolonged period of time.

**Why does a pressure sore develop?**

▸ When blood supply to the skin is cut off for more than two to three hours, a bed sore will start to form; the skin begins to die.

▸ As the skin dies, the sore area begins as a red, painful area, which then turns purple.

▸ Left untreated, the skin can break open and become infected.

▸ A pressure sore can become deep, extending into the muscle.

▸ Once a pressure sore develops, it is very slow to heal.

▸ Pressure sores often occur in the buttocks area, on the sacrum or iliac crest, or on the heels of the feet.

▸ Pressure sores are also called *Bed Sores* and result from *Skin Breakdown*.

*NOTE:  FIRST SIGN OF SKIN BREAKDOWN can be identified by noticing if an area of the body stays RED or PINK following the removal of the pressure to that area.*

**What Causes Skin Breakdown?**

Caused by a combination of:
▸ Pressure
▸ Friction
▸ Weight of the body
▸ Body moisture

*Closely monitor areas of pressure.*

**8 Steps to Prevent Skin Breakdown:**

Step 1: Turn and reposition the person who is bedridden at least once every two hours. Place a pillow between the knees when legs are pressed together. (Prolonged pressure to the skin causes bedsores.)

Step 2: Inspect parts of the body where bedsores are most apt to occur: the heels, sacrum, knees, ears, shoulders and hips. Any sign of redness should be cause for concern. Keep weight or pressure off any reddened spots, until all signs of redness are gone.

Step 3: Keep the head of the person's bed flat, as much as possible when sleeping. (Raising the head causes the body to slump down deeper into the bed, which increases shearing force on the skin.)

Step 4: Use pressure-reducing aids in a bed or wheelchair. (Mattresses and seat cushions containing sheepskin, foam, gel or air reduce pressure on the skin.)

Step 5: Clean skin as soon as it becomes moist from perspiration, excrement or wound drainage. (Dampness that is allowed to linger on the skin increases the chance of skin breakdown.)

Step 6: Change sheets frequently. Choose sheets that are wrinkle-free and softened.

Step 7: Massage the skin two to three times a day to increase circulation. Apply lotion liberally. Avoid massaging bony prominences.

Step 8: Maintain adequate hydration. (For optimal skin health, the body needs at least eight glasses of water a day.)

**Treatment for Pressure Sores:**

Specific treatment of a pressure sore is determined by the physician based on the severity of the condition. Treatment is more difficult once the skin is broken.
- Remove pressure on the affected area.
- Protect the wound with medicated gauze or other special dressings as ordered.
- Keep the wound clean.
- Use medications (antibiotics) to treat infections. Serious bacteria can enter a pressure sore and can only be treated by antibiotics. To identify bacteria [i.e., Staph Infection, MRSA (Methicillin-resistant Staphylococcus aureus)], cultures must be ordered.
- Transplant healthy skin to the wound area.

**Stages of Bedsores: The Degree of Depth**

Stage 1 Bedsore: Changes in skin temperature (warmth or coolness), tissue consistency (firm or boggy feel), and/or sensation (pain, itching). The ulcer appears as a defined area of persistent redness in lightly pigmented skin. In darker skin tones, the ulcer may appear with persistent red, blue, or purple hues. A Stage One bedsore is a warning to caregivers and/or family members, because bedsores develop quickly and progress rapidly.

Stage 2 Bedsore: Partial thickness skin loss involving epidermis (top layer of skin), dermis, or both. At this stage, the ulcer is superficial and looks like as an abrasion, blister, or shallow crater. Once a bedsore gets past this stage it becomes much harder to treat.

Stage 3 Bedsore: Full thickness skin loss involving damage to, or death of, the subcutaneous tissue that may extend down to, but not through, underlying connective tissue (fascia). The wound will look like a fairly deep crater, black at its edges.

Stage 4 Bedsore: Full thickness skin loss with extensive destruction, tissue death, and/or damage to muscle, bone, or supporting structures (e.g., tendon, joint, capsule). Bedsore will look like a large, deep, open wound revealing bone and connective tissue.

**NOTE:  Prevention of Skin Breakdown is one of the main duties we all have.**

**What to do when you <u>first</u> notice skin breakdown:**

▸ You must <u>ALWAYS </u>document what you see, hear, smell or are told by the person or family member in the log notes.
▸ You must communicate a potential problem to your supervisor, also <u>document in your notes what your supervisor said</u>. The supervisor will report to the RN or the nurse consultant. The Nurse will communicate with the physician.
▸ You must follow up – what was said or done must also be documented. This follow up may take a period of day or longer, it is still your responsibility to document what actions were taken and what the outcome of your reporting was. Did the person get better, are there new orders, did the person go to the hospital? What happened as a result of your reporting a potential problem?

❖ **URINARY TRACT INFECTIONS**

**Urinary System components and related infections:**

▸ Bladder -- an infection in the bladder is also called *cystitis or a bladder infection*.
▸ Kidneys -- an infection of one or both kidneys is called *pyelonephritis or a kidney infection*.
▸ Ureters -- the tubes that take urine from each kidney to the bladder are only rarely the site of infection.
▸ Urethra -- an infection of the tube that empties urine from the bladder to the outside is called *urethritis*.

Urinary tract infections (UTIs) are important to watch for because they can cause a serious complication known as **sepsis.**

Sepsis refers to a bacterial infection in the bloodstream or body tissues. Sepsis caused by a UTI is one of the top leading causes of preventable conditions that can lead to the <u>premature death</u> of a person with a developmental disability. This is a <u>very broad term</u> covering the presence of many types of microscopic disease-causing organisms.

**Causes of Sepsis:**

▸ Sepsis can originate anywhere bacteria can gain entry to the body; common sites include the urinary tract, the liver and its bile ducts, the gastrointestinal tract, and the lungs.
▸ Broken or ulcerated skin can also provide access to bacteria commonly present in the environment. Invasive medical procedures, including dental work, can introduce bacteria or permit them to accumulate in the body.

▶ Entry points and equipment left in place for any length of time present a particular risk. Heart valve replacement, catheters, ostomy sites, intravenous (IV) or arterial lines, surgical wounds, or surgical drains are examples.

**The symptoms of a bladder infection include:**

▶ Cloudy or bloody urine, which may have a foul or strong odor (Note: If the person has a urinary catheter, cloudy urine can be easily seen in the catheter bag.)
▶ Low fever (Note: Not everyone will have fever.)
▶ Pain or burning with urination
▶ Pressure or cramping in the lower abdomen; (usually middle) of back
▶ Strong need to urinate often, even right after the bladder has been emptied

**If the infection spreads to the kidneys, symptoms may include:**

▶ Chills and shaking or night sweats
▶ Fever above 101 degrees Fahrenheit
▶ Flank (side), back, or groin pain
▶ Flushed, warm, or reddened skin
▶ Mental changes or confusion (Note: In the elderly, these symptoms often are the only signs of a UTI.)
▶ Nausea and vomiting
▶ Severe abdominal pain (sometimes)

**Treatment of UTIs:**

▶ Specific treatment of a UTI is determined by the physician.
▶ Treatment is more difficult if the UTI goes unrecognized for a long period of time.
▶ The physician may order more fluids, or specifically cranberry juice.
▶ The physician may also recommend drugs to relieve the burning pain and urgent need to urinate. [Note: Phenazopyridine hydrochloride (Pyridium) is the most common of this type of drug.]
  ▶ Medications (antibiotics) may be ordered to treat infections. Serious bacteria can enter the urinary track, sometimes <u>because of poor hygiene,</u> sometimes during <u>urinary catheter changes.</u> The physician will need to identify the bacteria (i.e., Staph Infection, MRSA) that may be the cause and cultures will be ordered.

**NOTE:  <u>Early DETECTION of a Urinary Tract Infection can save a Life.</u>**

**What to do if you suspect a person has a UTI:**

▸ First you must ALWAYS document what you see, hear, smell or are told by the person or family member in the log notes.

▸ You must communicate this to your supervisor, also <u>document in your notes what your supervisor said</u>. The supervisor will report to the RN or nurse consultant. The Nurse will communicate with the physician.

▸ You must follow up – what was said or done must also be documented. This follow up may take a period of day or longer; it is still your responsibility to document what actions were taken and what the outcome of your reporting resulted in.

**Other Medical Concerns to Watch for:**

▸ High Blood Pressure
▸ Seizures
▸ Stroke
▸ Osteoporosis
▸ Kidney/Renal Failure
▸ Arthritis
▸ Poor oral care
▸ Diabetes
▸ Fractures from falls

_____

**REPORTING -** Reporting is the verbal communication of observations and actions taken to the team or supervisor, usually in person or over the phone.

▸ A verbal report is given to a supervisor when the need arises, or for continuity of care (e.g., giving a verbal report to the next shift).

▸ It is always better to **report** something than to risk endangering the person, the agency, and yourself by not reporting it.

▸ Reporting helps your supervisor act accordingly.

**DOCUMENTING -** Documenting is the **written** communication of **observations** and **actions** taken in the care and supervision of the person.

**Remember:**

▸ If it was not documented, it was <u>not</u> done.
▸ Your job is not <u>over</u> until the paperwork is finished.
▸ The person's record is a <u>legal document.</u>

**Significance of Documentation:**

- A record of what was **done**, **observed**, and how the person **reacted.**
- Used for **evaluation** by other team members working on the support plan.
- Used to **clarify** complaint issues.

**Documentation Guidelines:**

- Always use ink.
- Sign all entries with your name and title, and the date and time.
- Make sure writing is legible and neat.
- Use correct spelling, grammar and abbreviations.
- Never erase or use correction fluid. If you make an error, cross out the incorrect part with one line, write "error" over it, initial it, and rewrite that part.
- Do not skip lines. Draw a line through the blank space of a partially completed line or to the end of the page; this prevents others from recording in a space with your signature.
- Be accurate, concise, and factual. Do not record judgments or interpretations.
- Make entries in a logical and sequential manner.
- Be descriptive. Avoid terms that have more than one meaning.
- Document any changes from normal or changes in the person's condition. Also, document what you informed the person's physician or your supervisor if indicated.
- Do not omit any information.

**Specific Forms:**

- Your supervisor will tell you about policies and procedures you need to know. Some agencies have specific forms you need to use for daily documentation.
- You will also need to learn other specific rules for reporting information regarding **incidents**. Your supervisor will give you more information on reporting incidents.

**COMMUNICATING WITH THE PHYSICIAN/NURSE - Tips for talking with Health Care Professionals:**

- Communication is a two-way street. You may find that at times the only good solution is to clearly state the problem. Unfortunately, some health care providers may not interact with you or the person you support in a positive or respectful manner, and it may be necessary to seek services elsewhere.
- A few strategies/tips may help you to clearly and efficiently communicate concerns and questions and avoid miscommunications:

**List of Strategies and Tips:**

- It is best to support self-advocacy rather than advocating for someone.
- In emergency situations, it is not always possible to take the time to prepare and plan for self-advocacy, but it is a desirable approach for most appointments.

- Make sure you ALWAYS know <u>why you are with</u> the person. Why is the person going to see this physician? <u>What is the reason for this visit?</u>
- Call the office prior to the appointment if accommodations may be necessary (e.g., Some people have great difficulty waiting for their appointment and may become agitated as time goes by in the waiting room; some people may have physical impairments that may require special accommodations for exams or tests.)
- **Role-play** asking questions and expressing concerns. This helps you or the person you support to feel more familiar and comfortable with the process and may enable you to identify barriers to clear communication before the appointment takes place.
- If you or the person you support has a great deal of anxiety about the visit, a **pre-visit** can be helpful. During a pre-visit, the person has the opportunity to meet the office staff and see the clinic so that it is not unfamiliar at the time of the appointment.
- Try to **stay calm**. Sometimes this is very difficult, particularly if the physician or office staff just does not seem to get your message, or if someone in the office makes an offensive statement. It is important to remain firm and be clear in what it is you are doing there.
- If you feel rushed into making a decision, or if the person you support appears to feel pressured, **it is okay to ask for some private time to discuss the options**. You may even need to call back with an answer at a later date. This is a perfectly acceptable way to ensure that you or the person you support has freely been provided informed consent.
- Always make sure that **you understand the physician's orders and know what was done at the visit** so that it can be **documented** in the person's record.
- It is **okay to ask the physician or the office staff for clarification;** <u>it is the only way to ensure that you will be communicating the proper information to your supervisor</u>.
- Most importantly, know that you have resources if you feel that you and/or the person you support have/has been unfairly or even abusively treated due to a disability status.
- All states have a Protection and Advocacy agency – see the National Disability Rights Network website at <u>www.napas.org</u> to find out more information.

**REVIEW - The TOOLS to Use When documenting:**

**Observation** – Use all senses: sight, hearing, touch and smell.
**Communication** – Ask questions and listen to answers. A good listener hears the words and notices other ways of communication, including noticing changes in behavior.
**Written Forms –** Document on forms designed to help you address information that you need to share with other staff and/or agencies.

- It is important that we, who provide services, know that the person we support was seen by a <u>physician and what was done or ordered.</u>
- It is still our responsibility to document any changes so that the plan of support can be updated. Case managers cannot do their proper job without proper communication of any changes that may indicate a need for additional services.
- Document what the family tells you about the visit to the physician and/or emergency room, and report this to your supervisor.

**SAMPLE: DIRECT SERVICE WORKER DAILY PROGRESS NOTES**

Person's Name: _____     Date: _____
Agency: _____     Shift Time: _____
Staff Signature/Title: _____

| **Document Medical Concerns** | *Examples of occurrences to document in this section include: person taken to E.R.; complaints of medical problems such as congestion, difficulty swallowing, headache, sore throat, seizures, any symptoms you notice, cough, runny nose, red marks, etc. Any physician appointments (IF Physician visit, fill out Physician Visit Form).* |
|---|---|

_____
_____

| **Vital Signs** | **ONLY IF REQUIRED BY PLAN OF SUPPORT** | Time | Temp. | Pulse | Resp. | B/P | Weight |
|---|---|---|---|---|---|---|---|
| Medication Explanations: **complete if applicable** | | *Do NOT write out the regularly prescribed medication, see MAR.* | | | | | |

Refills today:     ☐ Yes   ☐ No     Name of med:_____
D/C Meds today:  ☐ Yes   ☐ No     Name of med:_____
New Orders:      ☐ Yes   ☐ No     SEE ORDERS

**DOES PERSON REQUIRE ASSISTANCE WITH TOILETING?     YES ☐          NO ☐**
**If yes, note time(s) and assistance provided: Time(s):          What assistance:**
**Bowel Management:  BMs this shift: ☐ Yes    ☐ No**
**Fluid Balance-Urine: List how many times person voided this shift: _____  or Catheter: empty each shift**

**DIETARY NOTES:**
**Type of Diet:** [ _____ ]   **List percent eaten at each meal: 25%, 50%, 75%, 100% or 0% for refusal to eat**

List time person ate before each meal:     List percent eaten at each meal:     Any Snacks? What?     When?
_____ Breakfast          _____%          _____     _____
_____ Lunch             _____%
_____ Dinner            _____%   Peg/ G-Tube? _____ Formula: _____Rate: _____

**Personal Contacts:    ☐   Friends          ☐   Family          Name(s) of Contacts:**
 **Type of Contact:     ☐   Phone          ☐ Visit**

**PERSONAL TASK COMPLETED:  *Note time when each completed; Leave blank if person is independent.***
_____ **Bathing**        _____ **Dressing**        _____ **Brushing Teeth**        _____ **Nails Clipped**

_____ **Brush/Comb hair**        _____ **Ears Cleaned**        _____ **Turned in bed/change W/C positions**
**Other:  (Specify)_____**

**TASK COMPLETED:  *Note time when each completed: either by staff or person supported (If applicable).***
_____ **Meal Preparation**     _____ **Sweeping/Mopping**     _____**Dishes**     _____**Laundry**     _____ **Dusting**

_____ **Disinfect/Clean Bathroom (toilet, tub, sink)**     _____ **Vacuum**     _____ **Make bed**     _____ **Other(Specify)**

**ACTIVITIES RELATED TO PLAN OF SUPPORT:** *(What activities occurred that are outlined in person's POS)*
**Attended day program/work?    ☐ Yes     ☐ No**
**Other:_____**
**ACTIVITIES: (*What did the person do, who did they see?*)**
**List Contacts with community:**

**Any Incidents: - incident form filled out: related to: ☐ Medical     ☐ Behavior   ☐ Seizure**
 **☐ Abuse/Neglect    ☐ Other (Specify type:          )**

FILE PROGRESS NOTE PER SHIFT / COMPLETED DAILY LOG FOR STAFF COMMUNICATION ☐ Yes     ☐ No

**SAMPLE: PHYSICIAN VISIT - COMMUNICATION FORM**
**Agency Name, Address and Phone Number**

| Name: | Date of Visit: |
|---|---|
| Medicare/Medicaid No: | DOB: |

| Pertinent Medical History / known diagnosis: | |
|---|---|

| Allergies – Medication/Food – (listed on current MAR attached) |
|---|
| Current Medications: PLEASE SEE CURRENT MAR (Medication Administration Record) ATTACHED |
| REASON FOR THIS VISIT/ COMMUNICATION: (Staff <u>must</u> complete this section if this is a visit – ex: Follow up, 90L, illness) |

**Note:** For Annual Physical, 90L form must accompany this form and be filled out by physician. Physician should order all annual blood work, including CBC. Individuals with previous positive TB reading must have Chest X-Ray every 5 years and documented chest auscultation noted at each physician visit.

| (PRINT)<br>Physician Name: | Specialty: |
|---|---|
| Address: | Phone: |

PHYSICIAN ASSESSMENT AND ORDERS: (attach additional sheets as needed)

*TEST ORDERED:(if any)*_____

**Staff: check all that apply:**
_____ No Medication changes                    Follow-up date: _____
_____ Readable assessment and orders
_____ New medication: make sure time limits are understood
_____ Blood work: ensure copies of results are sent to Provider Agency
_____ Additional sheets attached if needed
_____ Progress note and communication logs filled out regarding this visit

**Staff Signature:** _____    **Physician Signature:** _____

## Staff Checklist for each Physician Visit

DSW: Use this form as a reminder of all components needed when visiting the physician.

Please complete the following checklist:

_____ Copy of Medicaid/Medicare card, MAR and this form given to physician.
(If annual physical, make sure you also bring 90L form)

_____ Make sure physician completes appropriate sections of Physician Visit form.
(If Physician refuses to sign form, make sure you write what physician said and that you clarified with physician or staff what you need to report to your supervisor about this visit.)

_____ Make sure physician writes prescriptions for medication changes, if any, and includes discontinuation (D/C order) of any medication(s) in physician orders.

_____ Secure a written prescription from the physician before leaving the office, if applicable, and clarify all recommendations and orders.

_____ After visit, make copy of prescription or D/C order, if applicable per your agency policy, and copy of Physician Visit form; give original orders and forms to your supervisor who will notify the Nurse of medication changes that need to be made to MAR as well as any recommendations and tests noted.

\_\_\_\_\_ Copy of all orders and this form are to be filed in person's chart immediately per agency policy.

\_\_\_\_\_ [Supervisor will assure new medications are ordered.]

_____ Document in the staff communication log the details of medication changes as well as on the Daily Progress note; do not forget to add other orders that were made and sign so the next shift can review and be aware of changes that have occurred.

Staff and Supervisor are to sign below once they have completed and checked each of the above steps as applicable.

Staff Signature:_____ Date: _____


Supervisor:_____ Date: _____


Person's name:_____ Date of visit: _____

# QUALITY OUTCOMES

Evaluating and improving quality outcomes for people with developmental disabilities requires adoption of and adherence to a continuous quality improvement focus within each agency. Each agency will be different, and different processes and methods may be used. Core concepts in any quality enhancement approach must include:

1. Establishment of the agency mission and vision
2. Identification of quality outcomes
3. Development of performance indicators to assess the identified outcomes areas
4. Collection of data on the identified indicators
5. Analysis of the data (on an individual and agency level)
6. Assessment of the quality of supports provided as tied to the outcomes identified
7. Development of a quality enhancement plan with goals and objectives tied to the agency mission/vision
8. Selection of at least annual quality enhancement projects aimed at outcomes areas in need of improvement or identified barriers/challenges in meeting outcomes

### *Agency Mission and Vision*

Each agency must identify its own mission and vision. The mission and vision tell your potential participants, existing participants, staff and community what is important to your agency and the business within which you are invested.

An agency *mission* describes the purpose of the organization and should consider the following:

1. The nature of agency's business
2. The types of products or services provided
3. Agency's markets/customers
4. Agency's organizational culture

An agency *vision* describes a vivid picture of the organization as it effectively and efficiently carries out its mission. It should be outcome oriented and should consider the following:

1. What is the agency trying to accomplish?
2. What is the overarching goal the agency is trying to reach?
3. Why does the agency do what it does?

Each agency supporting individuals with developmental disabilities should have a mission and vision that is consistent with Louisiana's Developmental Disabilities Services System and that aligns with LDH/OCDD's mission and vision.

**LDH/OCDD Mission**:

*The mission of the Office for Citizens with Developmental Disabilities is to provide programmatic leadership necessary in the design and development of services to afford people with developmental disabilities and their families a seamless services system that is responsive to both individual needs and desires.*

**LDH/OCDD Vision**:

*A society that promotes partnerships and relationships which empower people with developmental disabilities to live fully integrated and valued lives.*

Once an agency establishes its mission and vision, the agency must consider the values and guiding principles that are priorities to the organization and its mission/vision. Consider the following in thinking about establishing values and guiding principles:

1. What drives your agency as it conducts business?
2. What are the constraints that your agency wants to impose on its activities?
3. What are the opportunities that your agency want to embrace?

As with the mission and vision, each agency should consider the core values and guiding principles of LDH/OCDD and ensure that the established values and guiding principles of the agency are supportive of and not in conflict with those of LDH/OCDD.

**OCDD's Values**:

1. *Accountability - People set goals, plan what needs to be done, do the work, monitor progress, report results, evaluate, exchange feedback and take responsibility for their actions.*
2. *Choice - People have the opportunity to learn about options and use this information to make their decisions.*
3. *Clarity - Openness, honesty and accountability in all services, supports and information. All information is known and understood by everyone.*
4. *Cultural Sensitivity - People regardless of cultural differences are to be treated with respect and dignity to fairly meet their needs.*
5. *Dignity - People are valued and the system supports their sense of pride and self-respect.*
6. *Empowerment - People act on issues they define as important.*
7. *Inclusion - People take part in their communities of choice, including taking part in policies and program planning.*
8. *Partnership - People work together in shared decision making to achieve common values.*
9. *Person/Family Driven Services System - People are at the center of the system and their needs and preferences determine how services are provided.*
10. *Quality - People achieve desired outcomes.*

**OCDD's Guiding Principles**:

1. *Developmental disabilities are a natural part of the human experience that does not diminish the rights of people to have control and choice over their own lives and fully participate in their communities or locations of choice.*

2. *The OCDD values all people and protects their rights and privileges as citizens of Louisiana and the United States of America.*

3. *People have the power to make decisions about services and supports, how they are delivered and by whom. The necessary services, supports and information are received promptly.*

4. *Services and supports are designed to allow people to remain in their communities or locations of choice, support people to achieve valued outcomes, develop meaningful relationships and attain quality of life as defined by the person.*

5. *Services are flexible, and personal outcomes and goals are considered in the development of individualized supports for each person.*

6. *Family supports enable people to live in stable environments with lasting relationships while existing natural supports and community resources are promoted and utilized.*

7. *The needs of the entire family are considered in the development of services and supports.*

8. *The OCDD system values and respects services agencies and workers who provide supports.*

9. *The OCDD system is easy to navigate, user friendly and culturally sensitive. People are able to access services, supports and information through a single point of entry, which is person-centered. The services system is a seamless, flexible and responsive system of various services and supports through various stages of life.*

10. *There is a partnership to assist with practices, communication, procedures, information and support so people who rely on services and supports feel confident that effective safeguards are in place and problems will be addressed quickly and effectively.*

11. *The OCDD promotes cost-effective delivery of services.*

12. *The OCDD is always seeking continuous improvement by which there is meaningful and consistent involvement by people in policy development, agenda and priority setting.*

As an agency considers its mission, vision, values and guiding principles, consideration of the areas covered in this handbook is an important step in moving toward an agency that has at its core a Person-Thinking mindset with a high expectation for positive quality of life outcomes as well as positive behavioral and general health for its participants.

*Stakeholder Engagement*

Each agency must identify methods for involving stakeholders including participants and their families in not only establishing the agency mission, vision, values and guiding principles, but also in the agency quality process. Stakeholder engagement may take many forms and can include the following:

1. Person/family satisfaction surveys

2. Routine review of agency complaints and/or participant and family requests
3. Inclusion of participants and their families on quality councils/committees
4. Inclusion of participants and their families on agency boards and other groups

*Identification of Quality Outcomes*

Within each agency's quality process, a core component starts with the identification of quality outcomes. Consider the following in identifying your agency's quality outcomes:

1. What does your mission, vision, values and guiding principles say the agency intends to do?
2. What do your participants (and their families) tell you is important to them?
3. What other requirements must you meet?

In considering the above, the areas covered in this handbook offer some common areas for quality focus that are consistent with what individuals with developmental disabilities and their families consistently note as being important (within both state and national forums). These areas include the following:

1. Achieving identified personal goals and independence
2. Establishing, maintaining and expanding relationships and community connections
3. Having access to and support for meaningful school, work and fun
4. Achieving improved health and behavioral health

For each outcomes area, performance indicators will need to be identified so that outcomes can be measured in a meaningful manner. Identification of performance indicators should begin with consideration of data that may already be available as well as data that could be available and measured. Options that should be considered to measure the areas included in this handbook include the following:

1. Quality of Life Tool
2. Person/family satisfaction surveys
3. Critical Incident Reporting
4. Complaints

You will also include and consider other data including results of any regulatory surveys.

*Collecting and Analyzing Data*

Once an agency establishes data available and needed, the data must be collected and analyzed. Each agency should establish the frequency with which data will be collected understanding that this may be different for each type of data and thus for each identified indicator. Additionally, the frequency of analysis and review of data must be established. Minimally, agency performance indicators should be reviewed on a quarterly basis except where data may only be available annually such as with satisfaction surveys or regulatory reviews.

*Developing a Quality Enhancement Plan*

Each agency's Quality Enhancement Plan must include all of the elements already covered in this section. Additionally, the review and analysis of performance indicators will assist in establishing needed agency performance improvement projects. Minimally, each agency should determine performance improvement projects annually. However, core issues that arise within a year and are important or may pose a risk if not addressed quickly should result in added performance improvement projects throughout each year. The agency quality enhancement process should be a continuous cycle of learning with evidence of improved outcomes over time.

*Using this Handbook to Address Agency Quality*

The areas identified in this handbook outline key areas in person-centered thinking, plan development, team functioning, meaningful activity/employment, and improvement in health and behavioral functioning. The guidelines noted in this handbook represent best practice in these areas and the tools in this handbook can be used to assist an agency in improving these noted areas and establishing and implementing best practices to support individuals with developmental disabilities. To achieve the best results in using these guidelines and tools, OCDD recommends and offers several opportunities to support ICFs/IID. These include the following:

1. Identification of core outcomes/data
2. Training
3. Technical Assistance
4. Consultation

Quality of Life outcomes and Critical Incident reporting to consider will be outlined in the next two sections. The Programmatic Unit will, at the request of LDH/OCDD and in coordination with Health Standards, complete random reviews of identified ICFs/IID which will include documentation review and site visits to look at the areas noted in this handbook and offer opportunities and suggestions for improvement which may include additional training, technical assistance and consultation that is available. Any ICF/IID may request access to these support options at any time. The final section of the handbook will provide detailed information about how these processes and requests will operate.

## Enhancing Quality of Life

If we are to know that we have been successful in supporting people to enhance their quality of life, we must implement tools/strategies to evaluate our progress in achieving individual outcomes. In this section, there are two tools that can assist in this process. The first, Quality of Life Indicators, allows an agency to evaluate from a record review/documentation perspective if we have achieved outcomes as identified in the plan of support. The second tool, an individual satisfaction survey, allows us to directly get feedback from the people supported related to how

we are doing as an agency. The combined implementation of these tools allows agencies to evaluate overall where they are successful in terms of the provision of supports and it also allows us to evaluate whether what we have in our plans/documentation is reflective of what is important to the person. This information should be evaluated overall at an agency level in order to identify minimally areas that the agency may want to strive for improvement in or to identify areas that the agency would like to target in terms of overall program enhancements.

| Quality of Life Indicator | 1 (Not at all/None) | 2 (Some but not as planned) | 3 (As desired/ needed) | If 1 or 2 is checked, code reason* | Is there a plan to address this issue | Was the plan modified at this review? |
|---|---|---|---|---|---|---|
| 1.  The person had contact with his or her family and friends. | | | | | | |
| 2.  The person has desired/needed supports for his or her home life. | | | | | | |
| 3.  The person participates in the life of his or her community including going to preferred (fun) places. | | | | | | |
| 4.  The person works/volunteers/has learning experiences consistent with his or her goals and desires. | | | | | | |
| 5.  The person's rights are protected and he/she has opportunities, support and assistance for self-advocacy. | | | | | | |
| 6.  The person had choices within his or her day. | | | | | | |
| 7.  The person has learned new skills that increase his or her independence. | | | | | | |
| 8.  The person is medically stable. | | | | | | |
| 9.  The person has no behavioral or psychiatric challenges or has experienced decreases in these. | | | | | | |
| 10.  The person has access to preferred (fun) items, activities, and people. | | | | | | |
| 11.  All needs are being met based upon individual/family support and support team review.  If not, specify unmet need: | | | | | | |
| 12.  The person has made progress toward his/her personal goals or the person or those who know him or her best report that quality of life has improved.  Specify any goal for which the person is not making progress: | | | | | | |

| * Reason Codes:  Note if 5 is coded, specify reason. | 1- (Access to supports) | 2- (Trans-potation) | 3- (No funding) | 4- (Not done as planned) | 5- (Other) | |
|---|---|---|---|---|---|---|

# Satisfaction Questionnaire

| Person's Name: | | Date of Completion: | _____ <br> *(Month/Date/ Year)* | ☐ Visit | ☐ Phone Call |
|---|---|---|---|---|---|

| | |
|---|---|
| **Who supplied answers?** <br> *(choose one only)* | ☐Person      ☐Family Member      ☐Staff Member <br> ☐Other (please list:_____) <br> ☐Combination of above (please list: _____) |
| Provider Name: | |
| Number of beds in home: | ☐ ≤6      ☐ 7-15      ☐ 16-32      ☐ 33+ |

| QUESTIONS | Probes | Yes | No | NOTES |
|---|---|---|---|---|
| Do you have contact with your family and friends? | Is it as much as you want? <br> Who do you want to see/talk to more? | | | |
| Do you participate in community activities? | Do you go to preferred places? <br> Do you participate in preferred events? | | | |
| Do you have opportunities, support and assistance for self-advocacy? | What roles do you have? <br> Do you want to have others? <br> Do you have privacy when/how you want? | | | |
| Do you have choices within your day? | Probe areas like: schedule, meals, leisure and recreational activities, etc. | | | |
| Do you have access to preferred/fun items, activities, and people? | Does your staff know the things and people you like? <br> Do they help you get these things or see these people? | | | |

| QUESTIONS | Probes | Yes | No | NOTES |
|---|---|---|---|---|
| Do you have the information you need to help in your planning? | Is the information you get easy to understand? | | | |
| Does your plan have the supports for things you want the most? | What matters most to you? What do you want more of? | | | |
| Can you talk to the people you need to for your plan to change? | Do you know who to talk to about your plan? Can you reach them when you want to? | | | |
| Does your staff communicate with you in ways you understand? | Do they know how you communicate best? Do they understand you if you talk or sign? | | | |
| Can you see a doctor or therapist if you need to? | Do you have to wait awhile? Do you have any problems now? | | | |
| Do your supports help you have a good life? | Is there anything you want that you don't have now? Is there anything you are worried about? | | | |

Interviewer:

LOUISIANA
DEPARTMENT OF
HEALTH

**Promoting Health and Safety:  Critical Incident Reporting and Response**

A commitment to offering quality services that promote each person's opportunity for personal growth and freedom means we must also evaluate critical incidents and responses to those incidents. There is a need for uniformity and consistency in the reporting of, responding to, tracking of, and follow-up activities related to critical incidents for the persons we are supporting.

Types of Reportable Incidents:

- Abuse
- Death
- Exploitation
- Extortion
- Fall
- Involvement with Law Enforcement
- Loss or Destruction of Home
- Major Behavioral Incident that may include attempted suicide, suicidal threat, self-endangerment, elopement/missing, self-injury, property destruction, offensive sexual behavior, sexual aggression, or physical aggression.
- Major Illness that may include bowel obstruction, decubitus, pneumonia, or seizures.
- Major Injury
- Major Medication incident such as staff error, pharmacy error, person error, or mediation non-adherence
- Neglect
- Restraint Use such as behavioral restraint or medical restraints (i.e., chemical restraint, mechanical restraint, or personal restraint)
- Self-Neglect
- Health care admissions such as acute care facility, emergency room, nursing home, psychiatric hospital, rehabilitation facility, and/or Respite Center/Supports and Services Center

It is our responsibility to respond to any type of critical incident. To be effective in providing supports, it is important that we not only identify and report each incident, but we also need to evaluate each incident to promote health and safety and prevent further incident where possible. In the implementation of systems to track the incidents as well as capture our response to the incidents, we are often able to identify trends and patterns on an individual basis as well as agency wide. Having strong practices and processes in place allows teams to effectively identify, on an individual basis, strategies to mitigate risk where possible to increase overall quality of life. Often this information can be utilized by an agency to identify areas that may need to be evaluated for overall system changes or quality enhancement areas to be addressed. To understand what we need to improve upon, we must have mechanisms to identify where there are problems.

**Accessing OCDD Support**

The following activities are available to assist in the areas identified in this handbook and can be accessed via the Programmatic Unit:

1. Training
2. Technical Assistance
3. Consultation

This section outlines how these may be requested and what may occur if an agency is selected for random monitoring.

*Training*

The Programmatic Unit will offer annual training in the following areas throughout the state:

1. Person-Centered Thinking
2. Meaningful Activities
3. Team Process
4. Positive Behavior Supports
5. Promoting Health and Recognizing Signs and Symptoms of Illness

OCDD will send notification of all scheduled trainings and locations to all ICF/IID providers as they are scheduled each year. Providers may also request agency specific training using these modules. To request training, an ICF/IID should follow the process outlined in the ICF/IID Programmatic Unit Intake Process section of this handbook.

Customized training may also be requested and if within the scope of the Programmatic Unit, the training will be developed and providing using a similar process. If the requested training necessitates involvement of other OCDD areas, the Programmatic Unit Program Manager will coordinate with the identified OCDD point person. If the requested training involves specialized clinical expertise outside the scope of the Unit, the Program Manager (or designee) will coordinate with the OCDD Resource Center to receive the request and collaborate.

*Technical Assistance*

The Programmatic Unit will also provide technical assistance to ICF/IID agencies to implement and use the guidelines and tools contained within this handbook. Typically, technical assistance will be initiated in the form of an agency identifying some areas within the guidelines and tools of this handbook that the agency wishes to implement. Often, technical assistance will begin with some amount of training to introduce the guidelines and tools and set a foundation for the agency and its staff to use them. Technical Assistance will involve more hands-on and direct involvement with an agency in implementing specific guidelines and tools of interest or those identified as important within a specific monitoring or review process. To request technical

assistance, an ICF/IID should follow the process outlined in the Programmatic Unit Intake Process section of this handbook.

If the requested technical assistance necessitates involvement of other OCDD areas, the Programmatic Unit Program Manager will coordinate with the identified OCDD point person. If the requested technical assistance involves, specialized clinical expertise outside the scope of the Unit, the Program Manager (or designee) will coordinate with the OCDD Resource Center to receive the request and collaborate.

*Consultation*

Consultation refers to a more general request for assistance in reviewing an individual situation and/or agency area. The ICF/IID may know there is an area or a particular person with which they are not getting the outcomes they are seeking, but are unsure of what may underlie the challenges. Requests for consultation will occur as outlined in the Programmatic Unit Intake Process section of this handbook and will be consistent with the process for any LDH/OCDD initiated review/site visit.

If the requested consultation necessitates involvement of other OCDD areas, the Programmatic Unit Program Manager will coordinate with the identified OCDD point person. If the requested consultation involves specialized clinical expertise outside the scope of the Unit, the Program Manager (or designee) will coordinate with the OCDD Resource Center to receive the request and collaborate.

**ICF/IID Programmatic Unit Intake Process**

The Programmatic Unit will receive referrals through several sources: Pilot Sample, CEA (Cooperative Endeavor Agreement) Providers, Office for Citizens with Developmental Disabilities (OCDD) Central Office, Louisiana Department of Health (LDH) Health Standards Section, or directly from a provider.

This section describes the steps in the process to initiate services with a provider through the Programmatic Unit.

*Request Received:*

All requests for Programmatic Unit services should be sent to the unit Intake Coordinator via email at ICFProgramUnit@la.gov or by phone at 225-567-1248. After receipt of the request, the intake coordinator will first determine if the source of the referral is from Health Standards or OCDD Central Office. Any referrals from these two entities will immediately enter a crisis process. All other referrals will continue through the intake process.

*Provider Contact:*

Within one working day from receipt of referral request, the Intake Coordinator will:

1. Contact the provider to review the services of the Programmatic Unit, inclusive of time commitment required by the unit and the provider. A review of the intake process will also be discussed.

2. Based on the nature of the request including the identified need/service, priority of need will be determined. If the request fits a priority one referral, it will immediately be routed through the crisis referral process.

The first contact with the provider initiates the following:
  ▸ Determination of Priority
  ▸ Intake Form Completion
  ▸ Provider Self-Assessment
  ▸ Gathering needed provider information

*Prioritization of Referral:*

Due to the variety of referral sources and the varying levels of urgency for services, the Programmatic unit will prioritize all referrals.

The priority of case assignments will be indicated as follows:

| |
|---|
| **Priority 1** <br> • Providers with immediate jeopardy of health and safety. <br> • All requests originating from Health Standards or OCDD Central Office. |
| **Priority 2** <br> Providers in need of services related to basic health, safety, and wellness concerns. |
| **Priority 3** <br> Providers needing minor training and technical assistance in areas not related to health and safety. |

*Intake Form Completion:*

The intake coordinator will complete the ICF/IID Programmatic Unit form via phone with the provider.

*Provider Self-Assessment:*

To gain an understanding of a provider's support needs, a self-assessment will be completed at initiation of intake and again after services provided by the Programmatic Unit are completed.

The Intake Coordinator will send the provider a self-assessment form via email on the same day the intake form is completed. The provider will be given 10 working days to return the form to the intake coordinator via email (ICFProgramUnit@la.gov) or fax (225) 567-1257.

*Gathering Needed Provider Information:*

During the initial telephone call with the provider, the intake coordinator will request all necessary records needed for case assignment. The provider will have 10 working days from this request date to return all records to the intake coordinator via email or mail.

Records requested from the provider may include (at minimum):
- Provider's Quality Enhancement Plan (QEP)
- Provider's Plans of Care (POC)
- Critical Incident Reports (CIR)
- Any other pertinent documentation

**Crisis Referrals**

All Priority One requests for services will be determined a crisis referral and routed immediately upon determination of such to the Program Manager of the Programmatic Unit.

Within 1 to 3 working days of receipt, the Program Manager will assign the crisis case to the Programmatic Unit.

**Louisiana Department of Health**
**Office for Citizens with Developmental Disabilities**
**ICF/IID Programmatic Unit Intake Form**

| For OCDD Staff Use Only | ☐ Referred to Resource Center |
|---|---|
| Date Received: | Notes: |
| Date Assigned: | |
| Staff Assigned/Team Lead/Regions: | |
| Pre Self-Assessment<br>Date Sent:<br>Date Due:<br>Date Received: | Referral Source:<br>☐ *Provider (self-referred)*    ☐ *CEA Home*<br>☐ *OCDD Central Office*    ☐ *Pilot Provider*<br>☐ *LDH Health Standards*<br>☐ *Other (please specify):* |

| Provider Information | | |
|---|---|---|
| Provider Name: | | Region: |
| Main office Address: | | |
| City: | State: | Zip: |
| Phone #: | Fax #: | Main Email: |
| Director Name: | Director contact info: | |

## Reason for Referral

*What led you to contact us?  How long has this been a concern?  Is this a recurring or new concern?  Have there been safety issues due to medical or behavioral challenges?  Are there legal issues involved? (Attach more pages as needed)*

☐ Recent Deficiencies from Health Standards? List all below:

## Desired Outcome:

*What is the nature of the referral?  What is the outcome you want to achieve with this referral? (Attach more pages as needed)*

**Louisiana Department of Health**
**Office for Citizens with Developmental Disabilities**
**ICF/IID Programmatic Unit Intake Form** *Continued*

*12/07/2017 AW*

| Community/Group Home Information |
|---|
| *Please list information for each home you are requesting services for. If needs for each home vary, please indicate in the referral needs section. If the referral needs are the same for every home, complete this box on the first referral home only. (Attach more pages as needed)* |

| Home Name: | | | | Region: |
|---|---|---|---|---|
| City: | | State: | Zip: | |
| Phone #: | Fax #: | Main Email: | | |
| Home Manager: | | Home Manager contact info: | | |

| | # Staff Employed at Home: |
|---|---|
| ☐ *Medically Fragile Home*<br>☐ *Complex Care Rate*<br>☐ *Pervasive Plus*<br>☐ *Other (please specify):* | Size of Home (# of individuals living in home):<br>☐ ≤6  ☐ 16 to 32<br>☐ 7 to 15  ☐ 33+ |

Referral Needs for this Home:

# of Critical Incidents (CIR) in last 6 months: ☐  Explain:

# REFERENCES AND SUPPORTING MATERIALS

**Louisiana Office for Citizens with Developmental Disabilities (2012).** *Guidelines for Support Planning.*

**Louisiana Office for Citizens with Developmental Disabilities (2017). About Us.** http://www.ldh.louisiana.gov/index.cfm/page/132.

**Reid, D.H. and Parsons, M.B. (2017).** *Quality Activities in Center-Based Programs for Adults with Autism.* **Academic Press, Elsevier Science.**

**Support Development Associates (2017). Person-centered Thinking Toolkit.** http://sdaus.com.

**Healthy People 2020. Healthy People 2020 Framework. The Vision, Mission, and Goals of Healthy People 2020. Overarching Goals.** http://healthypeople.gov/2020/