QIDP Professional TRAINING

IDHS
Illinois Department of Human Services

Module 1: Introduction to the World of the QIDP

Module 2: Leadership and Communication
Module 3: Behavioral Supports
Module 4: Person Centered Planning
Module 5: Record Keeping
Module 6: Advocacy, Rights, and Resources
Module 7: Environmental and Safety Supports
Module 8: Medical Supports
Module 9: Rules and Regulations

Module Overview

Module 1 Introduction

Why are you being trained to be a QIDP?

You are participating in QIDP training so that you may support people with intellectual and developmental disabilities effectively as a Qualified Intellectual Disabilities Professional. QIDPs are responsible for many tasks including ensuring that the people they serve receive individualized, appropriate, and person-centered services. This training is designed to give you an overview of the QIDP role as well as helpful tools, tips and resources.

Objectives

Participants will be able to:

- Describe the necessary qualifications of a Qualified Intellectual Disabilities Professional.
- Identify the annual continuing education requirements of a QIDP.
- Exhibit a brief understanding of the history of the field of human services as it pertains to intellectual disability professionals.
- Explain the four pivotal elements of the QIDP role.
- Describe and explain the fundamental roles and responsibilities of a QIDP.
- Determine how positive psychology plays a part in the role of a QIDP.
- Recognize the importance of time management and effective time management strategies.

Modules were written in partnership with Training Directors and training professionals at Trinity Services, Inc., Anixter Center, Clearbrook, Community Service Partners, Ray Graham Association, and DD Homes Network.

QIDP TRAINING

“Man’s mind, once stretched by a new idea,

never regains its original dimensions.”

-Oliver Wendell Holmes

Qualifications of a QIDP

A Qualified Intellectual Disabilities Professional (QIDP) must have at least one year of experience working directly with people with intellectual and developmental disabilities, meet the minimum federal educational requirements for a QIDP outlined in 42 CFR 483.430, and must provide documentation of both education and experience.

Direct work experience may include, but is not limited to:

- Case management or activities that include involvement with individuals in daily, work or social activities
- Interactions with consumers in the implementation of individual service plans, education plans or behavior programs
- Gathering behavior program data by interacting with or observing consumers to determine appropriate program implementation
- Involvement with consumers in programming at residential, work sites and other venues.

Persons, who would meet QIDP requirements within a reasonable time, may gain QIDP experience under the direct supervision of a trained QIDP by assisting them in collecting or collating data, drafting paperwork, organizing or recording team meetings, etc. However, only QIDPs on the Department's QIDP database can be assigned full QIDP responsibilities (e.g., preparing ISPs, conducting meetings, assessing consumer progress, completing paperwork and signing documents that require QIDP approval). QIDPs cannot sign off on QIDP paperwork prepared by staff not approved as a QIDP, even if that staff meets QIDP requirements.

QIDPs are responsible for many things, not least of which includes ensuring that the individuals we support receive appropriate, effective, and individualized person-centered services. This training is designed to give you an overview of what your position will likely involve, as well as a wealth of tools, tips, and resources that you can utilize in provision of those services.

A minimum of 40 hours of training is required once placement on the IDHS database (commonly referred to as the QIDP Registry) has occurred. Q training consists of 9 separate modules that will be completed over the course of the next two to six months.

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As you move through the modules you will find several icons.

This icon is used when further discussion is needed.

This icon is used to indicate that relevant agency specific information should be discussed.

This curriculum is meant to be a starting point for your journey to be a QIDP. There is much more to be said about the topics in this curriculum than it is possible to cover in a 40 hour classroom experience. Each module contains a list of recommended reading and resources so that you may gain further knowledge.

The field of psychology and intellectual and developmental disabilities is forever evolving. To remain current, QIDPs need to be lifelong learners, interested in research, innovations and advances in the field. After completion of the nine modules and associated on the job training, QIDPs are required by The Division of Developmental Disabilities to obtain 12 hours of continuing education (CE) /professional development annually beginning in the State Fiscal Year following completion of this QIDP training program. Only 6 of the 12 hours can be earned inside the employing agency. However, all 12 hours may be earned outside the employing agency.

Topics must be related to the work of QIDPs, or issues affecting the field of intellectual and developmental disabilities or service provision and must be presented by persons qualified in the subject matter.

College credit courses must relate work of QIDPs, or issues affecting the field of developmental disabilities or service provision. CE hours earned for college credit courses equal the credit hours earned for the course, not the time spent in class. More information about CE opportunities and documentation is available on the IDHS website at http://www.dhs.state.il.us/page.aspx?item=45329

A Brief Historical Perspective

The Arc of Illinois, founded in 1950, has created a timeline describing the history of disabilities dating back to the 1930s. The timeline below, based largely on facts from the Arc of Illinois, reflects events as well as changes in conditions, language, and prevailing thoughts as they pertain to people with intellectual disabilities. For the full version of the Arc's history, please visit www.thearcofil.org/history.

1930's - People met in church basements and homes to provide support for families and voluntary day activities for their children with DD.

1950, September – ARC of the United States was founded as National Assn of Parents and Friends of MR Children

1950 – ARC of Illinois founded by local parent groups from around the state. Officially incorporated in October 1955 and became active at all levels as a voice of support and advocacy.

1960's – State institutions at Lincoln and Dixon housed over 10,000 people. Local ARC chapters spawned special education schools and sheltered workshops.

1970's -Illinois became one of first states to pass laws giving children with disabilities the right to a free and appropriate education. Groundwork was laid for the development of community living and day programs. Also, in the early 1970s, the definition for a Qualified Mental Retardation Professional (QMRP) was established as one of 49 principles set forth in a court decision, Wyatt vs. Stickney.

1990's- Advocacy organizations emphasize community inclusion, person-centered planning and self-determination.

2010 – Rosa's Law: President Obama signed legislation on October 5, 2010 changing the terms "mental retardation" and "mentally retarded" to "intellectual disability" and "Intellectually disabled" in various federal laws. It makes federal language consistent with that used by the U.S. Centers for Disease Control, the World Health Organization and the President's Committee on Individuals with Intellectual Disabilities.

What's in a name?

The term "QMRP" (Qualified Mental Retardation Professional) was used until "Rosa's Law" changed all references of "mental retardation" in Federal Law to the term "intellectual disability"; therefore the term "QIDP" (Qualified Intellectual Disabilities Professional) is now used federally. Effective January 1, 2012, Public Act 097-0227 required both the removal of the term "mental retardation" from the lexicon of Illinois state agencies and use of the term "QIDP" when referring to state staff serving in that capacity. However, you may also see the term QDDP (Qualified Developmental Disabilities Professional) used and in our Illinois State Operated Developmental Centers (SODCs), you will see the term HPC (Habilitation Program Coordinator) used.

Four Pivotal Elements of the QIDP Role

Communication

Effective communication is the backbone of service planning and delivery. Sharing of information is critical but so is the manner in which it is delivered. Diplomacy is a word that somewhat captures the component of communication referred to as “how you say it”. Diplomacy is the employment of tact to find mutually acceptable solutions to a common challenge, such as phrasing of statements in a non-confrontational, non-judgmental manner.

Discuss each of the bulleted points below. Give examples of diplomatic usage of each.

- Verbal Communication - What we say and how we say it.
- Non-Verbal Communication- What we communicate without words.
- Listening Skills - How we interpret both the verbal and non-verbal messages sent by others.
- Negotiation - Working with others to find a mutually agreeable outcome.
- Problem Solving - Working with others to identify, define and solve problems.

Organization

Organization improves efficiency, increases productivity, maximizes time and helps to prioritize the many tasks of a QIDP. There are many systems of organization. The way you organize is not as important as the fact that you do organize and do so consistently. QIDPs find themselves working in a variety of locations, with many people. You will attend important meetings, facilitate important meetings and correspond with other professional through email and telephone. Ultimately you are responsible for the record of the person supported and if you do not have a strong organizational system, you will find this more than a little challenging.

Davis Allen, in his book, *Getting Things Done*, offers a workflow diagram that can be helpful with both organization and time management. See **Appendix B**.

Discuss common barriers to organization. Ask participants to share their strategies to address those barriers.

- Feeling overwhelmed
- Procrastination
- Multi-tasking
- Jumping between tasks
- Getting hung up on a task
- Getting distracted

Facilitation/Coordination

A facilitator leads others to obtain knowledge and information, work collaboratively, accomplish objectives and reach mutually satisfying actions to complete a project or solution to issues. Skilled facilitators have powerful listening and communication skills. They contribute structure and process to interactions so groups are able to function effectively by encouraging participation, promoting mutual understanding and cultivating shared responsibility. Often facilitators act as a mediator, coach or moderator. The goal of a facilitator is to encourage others to think productively, to ask vital questions, to find solutions and/or to identify productive actions

Adaptability/ Flexibility

Flexibility in the workplace is about adapting successfully to changing situations and environments. You will need to be able to change your job role and responsibilities on short notice. You will need to think quickly on your feet and be able to multi-task. Being adaptable is to adjust oneself readily to different conditions or situations. It requires reacting quickly to changing circumstances and finding new solutions, persisting when unforeseen issues come up and dealing with changing priorities and deadlines.

> *"It is not the strongest of the species that survives, nor the most intelligent that survives. It is the one that is the most adaptable to change."*
>
> **-Charles Darwin**

My Roles and Responsibilities as a Q

Using your knowledge of QIDPs, check the responsibilities you may have in your position as a QIDP.

__Applying relevant rules and regulations
__Managing financial matters
__Training staff
__Facilitating the planning process
__Coordinating the planning process with all disciplines
__Completing the record review process
__Writing goals and objectives
__Participating in and scheduling daily activities
__Counseling individuals, guardians, and direct care staff
__Leading and chairing meetings
__Acting as a community liaison
__Facilitating estate planning and wills
__Monitoring the plan
__Writing and developing person-centered individual service plans
__Developing a quality enhancement process
__Intervening in crises
__Participating in the development of behavior intervention plans
__Assuring medical needs are met
__Supervising and leading team meetings
__Assuring rights and responsibilities are known and met
__Assuring due process is rights need to be restricted
__Keeping records
__Assuring quality of life, health, and safety are met
__Participating in and coordinating transition planning
__Sharing responsibility for direct service work
__Writing and delivering staff evaluations
__Holding staff interviews and hiring new staff
__Helping families apply for different types of funding
__Supervision of staff
__Assuring basic needs are met
__Scheduling staff training/monitoring training regulations
__Disciplinary actions for staff
__Ordering supplies for the house and managing inventory

It’s Not Just What You Do but *How* You Do It

The task list for QIDPs can be long and diverse. The role may look very different from provider to provider. Regardless, how you complete your job will significantly impact your success. The “*how*” will allow you to build effective relationships based upon mutual respect and trust, delivering to deadlines and achieving results. The “*how*” determines your personal credibility.

Discuss the National Association of Qualified Developmental Disability Professionals Code of Ethics below.

The National Association of
Qualified Developmental Disability Professionals

Code of Ethics

A Qualified Developmental Disability Professional (QDDP)/Qualified Mental Retardation Professional (QMRP)/ Qualified Intellectual Disability Professional (QIDP) is the key person responsible for drawing together family, friends, and staff, as well as marshalling resources and energy in order to enhance independence and improve the quality of life for the individuals they represent. It is a position grounded in the principles of servant leadership. The QDDP performs his/her duties with the strongest possible commitment to personal and professional ethics and standards of conduct. To assess, understand and support people in achieving important outcomes and goals in their lives, it is necessary to understand the responsibilities and values of one’s profession. The following Code Of Ethics is to be a guidepost helping QDDPs along this journey.

In all relationships, the QDDP promotes the individual’s welfare, dignity, and respect by consistently advocating for their right to self-determination. QDDPs work to assist each person in identifying and reaching their goals. Inherent in this responsibility is enabling individuals to advocate for their own concerns in appropriate and effective ways.

- The QDDP supports individuals in understanding their rights and works to ensure that they are free to exercise them. If needed, education regarding responsibilities in relation to rights is also provided.
- When assisting individuals to make informed choices, the QDDP obtains and provides all the information necessary in language and format that can be comprehended as easily as possible.
- Should an individual need assistance in making sound, safe decisions, through the appointment of a legal guardian, the QDDP keeps the appointed guardian aware of the person’s rights and opportunities to make choices.
- The QDDP is committed to assisting persons with disabilities in choosing and crafting a life supported by societal norms around age, intimacy, livelihood and community participation.
- The QDDP is committed to maintaining the highest standards of confidentiality.

- In the development of each individual’s goals or plans, the individual with the disability remains the key person in the process. The QDDP involves those persons who know and are committed to fully supporting the person being served.
- The QDDP facilitates the contributions of all staff including those professionally trained persons who are involved in the provision of supports and services.
- Whether as an organizational representative or independent practitioner, the QDDP interacts with others while maintaining the highest levels of responsibility, integrity, and standards of moral conduct.
- As a professional in the disabilities field, the QDDP is always prepared to partner and collaborate with colleagues. He/she provides guidance, training, motivation and instruction, as the situation requires.
- The QDDP proactively identifies any barriers to the achievement of positive outcomes for the persons he/she represents and strives to remove or lessen those barriers or identify alternative pathways.
- The QDDP actively assists individuals to establish and maintain meaningful relationships with family members and persons with and without disabilities in their local communities.

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- In order to provide the best possible services, the QDDP will demonstrate his/her pledge to continued learning by consistently seeking ways to increase his/her knowledge of current trends and best practices.

> *"If your actions inspire others to dream more, learn more,*
> *do more and become more, you are a leader."*
> **-John Quincy Adams**

It's Not Just What You Do but *WHY* You Do It

You have probably heard the story about the three stonecutters who are asked what they are doing. The first one says, "I am cutting a stone." The second one says, "I am cutting this block of stone to make sure that it is square and its dimensions are uniform, so that it will fit exactly in its place in the wall." The third stonecutter, who is the happiest of them all, grins and replies, "I am building a cathedral."

Now is a good time to ask yourself why you want to be a QIDP.

Discuss the many reasons that participants became a QIDP.

While there are many paths to the role of QIDP there is but one purpose of all work completed by a QIDP. That work can be summed up in one question:

"How is Bob's life better as the result of my work?"

That is a very serious responsibility, not to be taken lightly. It is also a question that leads to many others questions:

- What is meant by better?
- Does better mean smarter or more independent?
- How do you define and measure better?

The science of positive psychology is looking at those very questions. Martin Seligman is largely considered to be the founder of positive psychology. In his book, Flourishing, he introduces the theory of well-being. He delineates between happiness and well-being (flourishing). Happiness involves how one feels in the moment, mood, how one might describe life satisfaction. Well-being, on the other hand is a combination of feeling good as well as actually having meaning, good relationships and accomplishment. There are the five elements of well-being:

- **P**ositive emotion
- **E**ngagement
- **R**elationships
- **M**eaning
- **A**ccomplishment

If the role of the QIDP is to make positive change in the lives of the people supported so that, indeed, their life is better today than a year ago, then Seligman’s elements of well-being are worth considering further.

Discuss Seligman’s five elements of well-being as they relate to you, your job and the people you support. If you have limited experience it is appropriate to consider these questions in terms of “What will you do to…” or” How will you…”

Positive Emotions can be viewed as happiness and joy. Positive emotions include peace, love, pleasure and curiosity. They are subjective and typically evaluated by self-report.

- Do the people you support experience positive emotions throughout their day?
- Do you recognize the benefits of laughter and seek to build laughter into the lives of people supported?
- How to you promote happiness in the daily lives of the people you support?

Engagement is associated with participation in activities such as sports, work, hobbies and spending time with friends. A person is more fully engaged when distractions are minimized or not noticed and concentration is high. Often a person’s level of interest determines level of engagement. Engagement is also primarily measured subjectively by self-report.

- Do you recognize the value of engagement in activity other than “programs”?
- Do the people you support have choice of activity across their day and lives? How?

Positive Relationships are at the core of well-being. Positive relationships with family, friends, neighbors and colleagues should be intentionally sought and fostered.

- Is your relationship with the people you support premised upon “fixing” their shortfalls?
- Do you and the direct support staff see your relationship with the people you support of a mother-child, teacher-student nature or are you a coach, mentor and ally?
- What have you done to create new relationships and strengthen existing relationships?

Meaning comes from a connection to a bigger cause, living for a greater purpose.

- How do you support people to make/strengthen connections to their preferred church or synagogue?
- How do you support people to contribute to their community?
- How do you support people in activities that are beneficial to them and others?
- How do you support people in systems or self-advocacy?

Accomplishment involves goal achievement, learning a skill or realizing a dream.

- Have you abandoned the developmental approach to personal growth and accomplishment?
- Do you know the dreams and life priorities of the people you support?
- Have you eliminated words and phrases such as running programs, 100% of the time and shaping?

My Roles and Responsibilities as a Q

Divide into small groups and brainstorm very specific strategies for assisting the people we support with flourishing based upon Seligman's PERMA model.

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Engagement is associated with participation in activities such as sports, work, hobbies and spending time with friends.
Positive Relationships are at the core of well-being. Positive relationships with family, friends, neighbors and colleagues should be intentionally sought and fostered.
Meaning comes from a connection to a bigger cause, living for a greater purpose.
Accomplishment involves goal achievement, learning a skill or realizing a dream.

Time Management

Never underestimate the power of positivity to increase your productivity. When you are more positive, people are more willing to help you, you are more confident, and you make better decisions. The role of a QIDP can bring many interesting and difficult challenges to your work day. These challenges may hinder both your positivity and productivity in the work place. Regardless, your focus on creating a better life for the individuals you serve shall prevail.

Paperwork, meetings, appointments, and visits can take up much of your work time. Implementing time management strategies that work well for you, your employees, your organization, and the individuals you support will keep you focused throughout even the most chaotic of days.

The Balancing Act: Balancing Paperwork and People

We all only have 24 hours in a day and if we get 8 hours of sleep we only have 16 hours. So the question becomes, "What do we do with those 16 hours?" Isn't it interesting how some people use those 16 hours to be incredibly productive while others accomplish very little?

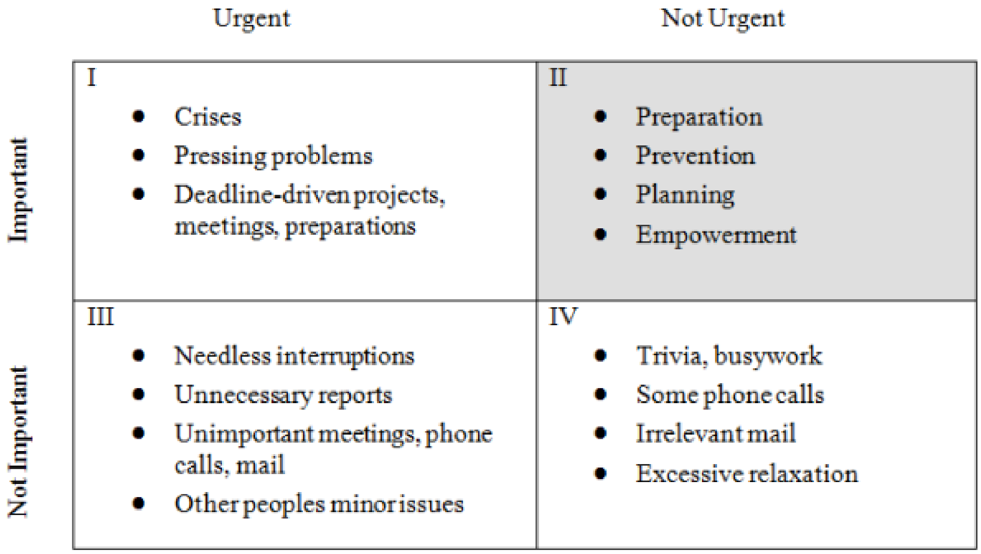
There are as many time management strategies as there are fish in the sea and more pop up every day. Below are a few tips for making the most of your work day.

1. Carry a schedule and record all your thoughts, conversations and activities for a week. This will help you understand how much you can get done during the course of a day and where your precious moments are going. You'll see how much time is actually spent producing results and how much time is wasted on unproductive thoughts, conversations and actions.
2. Any activity or conversation that's important to your success should have a time assigned to it. Appointment books work. Schedule appointments with yourself and create time blocks for high-priority thoughts, conversations, and actions. Schedule when they will begin and end. Have the discipline to keep these appointments.
3. Plan to spend at least 50 percent of your time engaged in the thoughts, activities and conversations that produce most of your results.
4. Schedule time for interruptions. Plan time to be pulled away from what you're doing. Take, for instance, the concept of having "office hours." Isn't "office hours" another way of saying "planned interruptions?"
5. Take the first 30 minutes of every day to plan your day. Don't start your day until you complete your time plan. The most important time of your day is the time you schedule to schedule time.
6. Take five minutes before every call and task to decide what result you want to attain. This will help you know what success looks like before you start. And it will also slow time down. Take five minutes after each call and activity to determine whether your desired result was achieved. If not, what was missing? How do you put what's missing in your next call or activity?

7. Practice not answering the phone just because it's ringing and e-mails just because they show up. Disconnect instant messaging. Don't instantly give people your attention unless it's absolutely crucial in your business to offer an immediate human response. Instead, schedule a time to answer email and return phone calls.
8. Block out other distractions like Facebook and other forms of social media unless you use these tools to generate business.
9. Remember that it's impossible to get everything done. Also remember that odds are good that 20 percent of your thoughts, conversations and activities produce 80 percent of your results.

The graphic below is another way to think about time management. It is taken from Stephen Covey's book *First Things First.*

Time Management Matrix:



	Urgent	Not Urgent
Important	I • Crises • Pressing problems • Deadline-driven projects, meetings, preparations	II • Preparation • Prevention • Planning • Empowerment
Not Important	III • Needless interruptions • Unnecessary reports • Unimportant meetings, phone calls, mail • Other peoples minor issues	IV • Trivia, busywork • Some phone calls • Irrelevant mail • Excessive relaxation

Quadrant I – Things that are Urgent and Important
Quadrant II – Things that are Not Urgent and Important
Quadrant III – Things that are Urgent and Not Important
Quadrant IV – Things that are Not Urgent and Not Important

Urgent means that a task requires immediate attention. These are the to-do's that shout "Now!" Urgent tasks put us in a reactive mode, one marked by a defensive, negative, hurried and narrowly-focused mindset.

Important tasks are things that contribute to our long-term mission, values and goals. Sometimes important tasks are also urgent, but typically they're not. When we focus on important activities we operate in a responsive mode, which helps us remain calm, rational and open to new opportunities.

Each of us has a choice as to how we will allocate our time between these quadrants. But one thing is for sure: when it comes to achieving your goals and living a life of minimal stress – all quadrants are NOT equal.

According to Dr. Covey, 90% of most people's time is spent in Quadrant I – things that are Urgent and Important, while the remaining 10% is spent "spacing out" the Not Urgent/Not Important Quadrant IV.

Covey believes that good time management and effective prioritization is simple: make sure you spend most of your time in Quadrant II.

My Roles and Responsibilities as a Q

Considering the job duties of a QIDP on page six of this module, complete the matrix below by placing tasks into the four quadrants.

Time Management Matrix

	Urgent	**Not Urgent**
Important		
Not Important		

Recommended Reading & Resources

Although we will try to cover a great deal of material with you today in class, the roles and responsibilities of a QIDP are broad and require continued study and attention throughout your career. We recommend the following resources as good places to start with regard to furthering your knowledge and understanding of this important role.

- Understanding Mental Disorders: Your Guide to DSM-5 by *American Psychiatric Association*
- Unforgotten: Twenty-Five Years After Willowbrook by *Danny Fisher and Jack Fisher*
- Direct Support Persons' Modules by *The Illinois Department of Human Services*
- Diagnostic and Statistical Manual of Mental Disorders: DSM-5 by *American Psychiatric Association*
- National Association of QDDPs, WWW.QDDP.org
- Flourishing by *Martin Seligman*
- Positivity by *Barbara Fredrickson*
- Getting Things Done by *David Allen*
- Universal Enhancement by *Tom Pomeranz*

Appendix A

Alphabet Soup

The Intellectual and Developmental Disabilities/Social Services field (perhaps more than any other) really, really loves its acronyms. You will hear quite a few acronyms, field-specific terms and jargon in your first few months as a Q. We like to call this "alphabet soup."

We hope you find this information helpful in your efforts to decipher the "new language." You will learn more as you go through each Module and then as you start to train on the job. If you have questions about an acronym or word you hear people use, or an acronym that isn't written out or explained in the workbook, please ask your supervisor or your instructor.

AAIDD - American Association on Intellectual & Developmental Disabilities. This is an advocacy organization which serves people with intellectual & developmental disabilities and their families through state and national chapters. Formerly known as American Association on Mental Retardation. (AAMR)

ABS - Adaptive Behavior Scale. A skill assessment used with people who have developmental disabilities.

Accreditation - Official approval of an organization by an independent reviewer such as the Commission on Accreditation of Rehabilitation Facilities (CARF) or the Council on Quality and Leadership (CQL).

ADA -Americans with Disabilities Act. A law guaranteeing civil rights to people with disabilities.

ADL - Activities of Daily Living. This can include cooking, hygiene, cleaning, budgeting, etc.

ARC - An advocacy group for people with disabilities and their families. state, national and international chapters. (Formerly "The Association for Retarded Citizens")

Assistive Technology - Any device that helps someone be more independent. Communication devices, wheelchairs, specialized dishes and utensils, modified light switches, etc.

BA - **Behavior Analysis**. A branch of psychology concerned with data based decision-making. Or **Behavior Analyst**- a person who practices behavior analysis and uses the techniques to help people with developmental disabilities.

BALC - Bureau of Accreditation, Licensure and Certification. BALC monitors compliance with national accreditation requirements for community agencies funded by the Office of Developmental Disabilities or Office of Mental Health.

Billing - This term refers to the Medicaid reimbursement process through which services are funded based on the type of service and amount of time spent providing the service.

Bureau of Quality Management (BQM) - A Division of the Illinois Department of Human Services which is responsible for quality assurance of agencies.

CAN - Career Access Network. Reviews agencies for people with disabilities.

CARF - Commission on Accreditation of Rehabilitation Facilities. Provides accreditation standards and reviewers for organizations working in the human services field around the world.

CILA - Community Integrated Living Arrangements. A residential setting serving 8 or fewer individuals, designed to maximize incidental learning and independence.

Clinical File/Chart/Record - A chart or file where information is kept on each person served by the agency.

CMS - Center for Medicare and Medicaid Services. A federal funding and monitoring body providing oversight of ICFDD and the State of Illinois Department of Human Services. Formerly known as the Health Care and Finance Administration, CMS conducts occasional audits of social service agencies that receive federal funding. CMS also defines Medicare rules and regulations for DHS, DPH, HFS, CILA, and foster care.

CP - Cerebral Palsy. A type of developmental disability affecting muscle structures.

CQL - Council on Quality and Leadership, an organization that accredits service providers who offer outstanding quality.

CPR - Cardio-pulmonary Resuscitation. A medical technique used to restore breathing. An annual recertification is required for most employees.

CST - Community Support Team. This team is made up of concerned persons who support a person receiving services. The team includes the person and 18 Module can also include family or guardian, QDDP, direct support professionals, program director, nurse, etc.

DCFS - Illinois Department of Children & Family Services. This entity serves as a funding and monitoring agency for some programs serving children.

DD - Developmental Disabilities. A disability that presents at birth or childhood, which is life-long, and affects learning across several major life areas: capacity for independent living, economic self-sufficiency, mobility, learning, receptive and expressive language, self-care, and self-direction.

DHS/IDHS – (Illinois) Department of Human Services: DHS is one of Illinois' largest State agencies created in 1997 to provide Illinois residents with streamlined access to integrated services, especially those who are moving from welfare to work and economic independency, and others who face multiple challenges to self-sufficiency. It administers the Temporary

Assistance to Needy Families (TANF) and Supplemental Nutrition Assistance Program (SNAP) programs which provide cash and foodstamp benefits through Link cards. The Division of Developmental Disabilities (DDD) is the office of DHS that regulates services and funding provided to people with disabilities. DHS licenses or certifies other agencies to provide services and conducts survey visits to all programs at least once a year to ensure that those services are being provided. It also ensures proper credentialing and training of direct support staff and QIDPs. A facility or agency regulated by DHS may be funded by it or the Illinois Department of Healthcare and Family Services (HFS), often referred to as "Public Aid" or "DPA," HFS's former name.

DR - Department of Rehabilitation Services. A funding and monitoring agency for some programs and services, particularly Supportive Employment.

DPA/IDPA - Illinois Department of Public Aid. This entity is a funding and monitoring agency for many Medicaid programs and services.

DPH/IDPH - Illinois Department of Public Health. IDPH regulates and licenses ICFsDD and other health care facilities. It conducts a surprise survey visit at least once a year, and they also investigate allegations of abuse, neglect and exploitation in ICFs. Facilities must be licenses to provide services under IDPH. IDPH also maintains a registry of DSPs, their criminal background status, training programs and IDHS Office of the Inspector General (OIG) substantiated findings of abuse/neglect.

DSM V - Diagnostic and Statistical Manual 5th revision. A reference used by mental health professionals to list criteria for the diagnosis of mental illness.

DSP -Direct Support Professional. The DHS title for people who work providing daily assistance for people with intellectual and developmental disabilities.

DT - Developmental Training. A State of Illinois funding category for certain Adult Services programs.

EFE (Sometimes called 'E for E') - Equip for Equality. A "watch dog" organization that monitors human rights issues for persons with developmental disabilities in Illinois.

GAC and OSG – Guardianship and Advocacy Commission and Office of State Guardian: The Illinois GAC protects the rights and promotes the welfare of persons with disabilities. Services provided include legal representation, investigating complaints of rights violations and providing state guardianship for Illinois' population with disabilities through OSG.

Goal - An outcome that a person would be likely to attain in 3-5 years. This is different than an objective which is more short term and lasts about a year.

HRC – Human Rights Committee

IARF - Illinois Association of Rehabilitation Facilities. Association of MI and DD providers who meet to share information. State and national chapters.

ICAP - Inventory for Client and Agency Planning. This is a tool that evaluates the skill levels of persons with developmental disabilities.

ICF/DD- health facilities licensed by IDPH to provide 24-hour-per-day service to people with developmental disabilities.

ICF<16 -Intermediate Care Facility for 16 or fewer persons.

ID - Intellectual Disabilities. A condition that is associated with a below average IQ score and deficits in intellectual functioning, formerly known as "Mental Retardation."

IEP, ISP, ITP - Individual Educational, Service, or Treatment Plan. Almost everyone who participates in an educational, residential, employment, or day program has either an IEP, ITP, or ISP, which are integrated plans that serve as a "blueprint" for services. A person's plan outlines what staff will do with or for the person, how often it will occur, and describes how progress will be determined.

ISBE - Illinois State Board of Education. Regulatory agency for funding and monitoring of Illinois elementary and secondary schools.

ISC – Independent Service Coordination. The role of the ISC agency is to ensure compliance with applicable Federal and State laws, arrange for and conduct assessments, make necessary determinations regarding for services, educate individuals and families, and make referrals and provide linkage to appropriate and needed services.

The duties of the ISC fall into two main areas of support: Screening and Case Management. First of all, the ISC agency is responsible for screening and assessing individuals who are located in the geographic area assigned to them by IDHS. The ISC agents assist people with disabilities and their families in receiving funding and deciding on services. Once funding is received, clients have an ISC agent, who is an independent case manager for all services received by that client.

These services were formerly referred to as **Pre Admission Screening (PAS)** and **Individual Support, Service and Advocacy (ISSA).**

Job Coach - An employee who supports a person with a disability to learn job skills at a job site in the community.

Link Cards - A debit-type card for cash and SNAP (foodstamp) benefits issued by the State of Illinois to enable eligible people purchase qualifying goods, services, food, and pay living expenses the Link card can only be used by the person (payee) to whom it is issued and requires the entry of a personal identification number (PIN) .

LPN - Licensed Professional or Practical Nurse.

MAR - Medication Administration Record. Form used to record medication taken each day.

Medicaid – Okay, this is not an acronym, but it is still very important to know. Medicaid is a form of government-provided and funded health insurance. Medicaid is more comprehensive than just funding visits to the doctor however; care can include acute health care, respite services, rehabilitation therapies, assistive technology devices and other community based services and supports.

Medicaid is available only to certain low-income individuals and families who fit into an eligibility group that is recognized by federal and state law. In Illinois, some clients and their families are also asked to pay a small part of the cost (co-payment) for some medical services. This is called a "spend down."

Medicaid is a state administered program and each state sets its own guidelines regarding eligibility and services. In Illinois, Medicaid is administered by HFS (formerly "Public Aid"). For all clients who are eligible for Medicaid, it is important to always have a current copy of their Medicaid cards in our files.

Medicare – Medicare is a Federal government program that pays for, among other things, long-term care for the elderly and for the disabled who have received SSDI (see below) for two years.

Medicaid Waiver- This program allows federal dollars to be used byn states to run programs that were not originally covered under Medicaid

MHP - Mental Health Professional. A direct support staff with a minimum of 5 years of experience in the Mental Health field or a 4 year degree in Human Services.

MI - Mental Illness.

MR - Mental Retardation. A type of developmental disability. This term has largely been replaced with Intellectual Disability, a term preferred by advocates and required to be used by Illinois state agencies.

NAQ- National Association of QDDPs. An organization that provides networking opportunities, information, and education for QDDPs.

Objective - A short term learning goal meant to be achieved in a one year period.

OIG – Office of Inspector General: OIG assists agencies and facilitates in prevention efforts by investigation all reports of abuse, neglect and mistreatment in a timely manner, to foster humane, competent, respectful and caring treatment of persons with mental and developmental disabilities. OIG can be considered the "investigative arm" that looks into allegations of abuse, neglect and exploitation in CILA, DT, ES, and In-home CILA. The Illinois Department of Public Health (IDPH) investigates allegations of abuse, neglect and mistreatment in ICF environments, but the agency overall utilizes OIG's Rule 50 reporting guidelines and standards.

On-the-job (OJT) training - Refers to training which occurs on the job site.

OSG, OPG - Office of State Guardian or Office of Public Guardian. Entities which serve as public guardian for some people we support.

OSHA- Occupational Safety and Health Administration: Congress created OSHA to ensure safe and healthful working conditions for men and women by setting and enforcing standards and by providing training, outreach, education, and assistance. Among other responsibilities, OSHA enforces workplace safety controls, and requires annual training for all staff in Bloodborne Pathogens and Fire Safety.

PAS Agency and ISSA Agent- See **ISC** (Independent Service Coordination)

Personal Outcomes - Goals, dreams, and plans that people have for themselves.

PICA - A diagnosis that describes people who have an obsession with putting things in their mouths which others, without this disability, would not. Cigarette butts are an example.

POS - Physician's Orders Sheet. A list of current medications and treatments for a person receiving residential services.

PSW- Personal Support Worker

QDDP/QIDP - Qualified Developmental Disability Professional/ Qualified Intellectual Disabilities Professional. These persons have responsibility for services and support for persons with developmental disabilities. Also known as a case manager.

Respite - A program which offers support to families of persons with disabilities.

Rule - state or federal regulations and guidelines for programs. Rule 119 (DT) or Rule 155 (CILA) are examples.

SEP - Supported Employment Program. A program in which individuals are assisted in obtaining pre-vocational skills, employment, and support on the job.

SIB - Self-injurious Behavior. Behavior that causes a person to injure him or herself that could require a behavior plan.

SODC –State Operated Developmental Center

SSA – Social Security Administration: The Federal government agency that provides oversight and regulation for all social security benefits (retirement, disability, SSI, Medicare, survivor benefits).

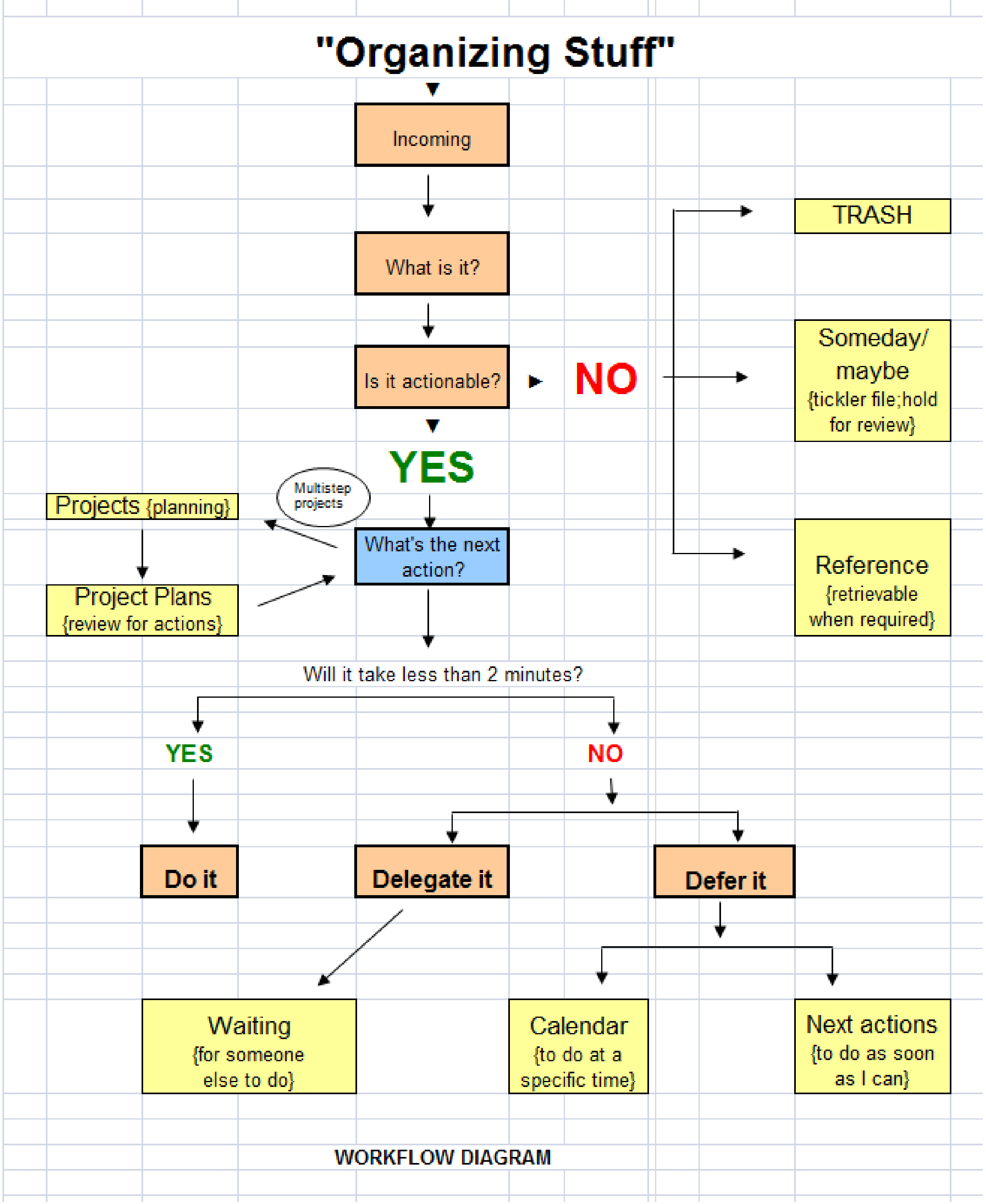
SSDI – Social Security Disability Insurance: Eligibility for these funds is based on ability to work. Beneficiaries of SSDI can be a disabled worker, the spouse of a disabled worker, the children of a disabled worker, or an adult disabled child of a worker. The amount received each month depends on the work history of the client and/or parent.

SSI – Supplemental Security Income: Eligibility for these funds in based on age (65 or older), disability, income and assets. Recipients are usually ineligible if their assets/income are over $1125.00 a month. If the client is legally blind, allowable assets are doubled to $2250.00. Eligibility for SSI often means the recipient is eligible for food stamps and Medicaid as well.

TD -Tardive Dyskinesia. An irreversible condition which occurs as a result of long-term use of some psychotropic medications. Can cause tics or other movement disorders.

Appendix B

Getting Things Done



Adapted from Getting Things Done by David Allen

QIDP Professional TRAINING

Module 1: Introduction to the World of the QIDP

Module 2: Leadership and Communication

Module 3: Behavioral Supports

Module 4: Person Centered Planning

Module 5: Record Keeping

Module 6: Advocacy, Rights, and Resources

Module 7: Environmental and Safety Supports

Module 8: Medical Supports

Module 9: Rules and Regulations

Module Overview

Module 2 Introduction

Why is leadership important to you, as a QIDP

First and foremost, a QIDP is responsible for assisting the people served to chart a path for increased independence, well-being and life satisfaction. This requires coordination of services, very often across programs, locations, disciplines and people. The job tasks can be as diverse as the people with whom you work but the one constant is the need for collaboration. There is an abundance of literature available which attempts to define leadership and virtually all definitions include “influence and inspiration of others”. As a professional whose success relies heavily upon collaboration, embracing your role as a leader will assist you in building strong relationships and inspiring commitment from others.

Objectives

Participants will be able to:

- Demonstrate an understanding of the guiding principles of the QIDP Profession.
- Apply principles of leadership to the responsibilities within their position.
- Identify leadership styles and their effectiveness for the position of a QIDP.
- Employ leadership behaviors based upon personal and professional values.
- Recognize the importance of effective communication techniques and strategies, as they pertain to the position.
- Utilize communication and body language to determine type of communication style.
- Describe how to facilitate an effective meeting between diverse groups of participants.
- Exhibit an understanding of leadership and communication techniques when given QIDP application scenarios.

LEADERSHIP

> *"Leadership is not about titles, positions or flowcharts. It is about one life influencing another."*
>
> - **John C. Maxwell**

4 Myths about Leadership

1. **The Management Myth:** Leading and managing are *not* the same thing. Much has been written about the differences between management and leadership.

   In this field and in your role, you will find that you need to be and should strive to be both an effective manager and leader. Ideally every manager would also be an effective leader and every leader an effective manager.
   Consider the following:

Leadership	Management
About influencing people	About systems and processes
Creates positive change	Maintains direction
Improves effectiveness	Improves efficiency
Focus is on the future	Focus is on today

2. **The Position Myth:** Leadership is not conferred by position or title. Leaders can be found in all levels of any organization. Position/title may give you the authority to complete certain tasks but will not make you a leader.

3. **The Knowledge Myth:** Often it is assumed that those with knowledge or mastery of a subject are leaders. Knowledge is necessary to be a leader but knowledge alone will not make a leader.

4. **The Pioneer Myth:** Being out front, at the top or the loudest does not make a person a leader. Unless the person out front or at the top has a following, the leader will emerge within the group.

Leadership Styles

Leadership style is the manner and approach of providing direction, implementing plans, and motivating people.

Kurt Lewin (1939) led a group of researchers to identify different styles of leadership. This early study has been very influential and established three major leadership styles: (Lewin, Lippit, White 1939)

- autocratic or authoritarian
- democratic or participative
- delegative or laissez-fair

Although good leaders use all three styles with one of them normally dominant, bad leaders tend to stick with the one style of autocratic.

Autocratic/Authoritarian

When leaders tell their employees what they want done and how they want it accomplished, without getting the advice of their followers, they are using an autocratic style. The Autocratic leader:

- Has an “I know best” attitude
- Is not interested in the personal goals of the members
- Discourages alternative ideas
- Does not encourage Discussion
- Makes all decisions
- Dictates work tasks
- Likes to be in control and in charge

Democratic

Democratic leadership involves allowing members of the group to share and contribute ideas. Democratic leadership, also known as ***participative leadership***, is a type of leadership style in which members of the group take a more participative role in the decision-making process. Researchers have found that this leadership style is usually one of the most effective and leads to increased group morale. The Democratic leader:

- Allows members to make choices

- Has a problem-solving style
- Creates a safe environment in which the members feel free to express their views, thoughts, and ideas without the fear of being ‘put down’
- Guides rather than directs
- Is receptive to members’ suggestions
- May offer alternatives or suggestions leaving most decisions to the group
- Is objective and fact-minded when praising/criticizing

Delegative or Laissez-faire

In this style, the leader allows the employees to make the decisions. However, the leader is still responsible for the decisions that are made. This is used when employees are able to analyze the situation and determine what needs to be done and how to do it. You cannot do everything! You must set priorities and delegate certain tasks.

- Has a “Let it be” attitude
- Remains more or less removed from the whole process
- Allows complete freedom for individual or group decision making
- Makes it clear he/she will only supply information if asked
- Makes infrequent comments on members activities unless questioned
- Makes no attempt to appraise or regulate the course of events
- Can produce independence among members but often low morale

What is your Leadership Style?

A good leader uses all three styles, depending on the forces involved between the followers, the leader, and the situation. Some examples include:

- Consider using an ***authoritarian*** style with a new employee who is just learning the job. This style is great when you are a good coach. The employee is motivated to learn a new skill. The situation is a new environment for the employee.
- Consider using a ***participative*** style with a team of workers who know their job. This style is helpful when you know the problem, but do not have all the information. For this style of be effective, the employees need to know their jobs and want to become part of the team.

- Consider using a ***delegative*** style with a worker who knows more about the job than you. You cannot do everything and the employee needs to take ownership of his/her job! In addition, this allows you to be more productive.
- ***Consider using all three*** by telling staff that a procedure is not working correctly and a new one must be established (authoritarian). Asking for their ideas and input on creating a new procedure (participative). Delegating tasks in order to implement the new procedure (delegative).

Other Important Points about Leadership

- ***Leadership is not about control***. Leaders lead others by inspiring them to commit to a worthy cause or endeavor.

- **Lead by Example** – Leaders are always "on stage" (even when you don't know it). One should use these opportunities to demonstrate good habits.

- **Integrity** – Leaders carry out their responsibilities with high levels of integrity and high ethical standards. Without integrity, employees will lose trust in your leadership. Employees must trust you for leadership to be effective.

- **Pro-activity** – Balancing each day's priorities with thinking about the future is a skill that separates weak leaders from strong leaders. Leaders avoid the temptation of operating in the 'crisis management' mode – becoming 'crisis junkies'.

- **Innovation –** Leaders are constantly looking at ways to do things better and to add value at every opportunity.

- **Personal Responsibility –** Leaders take responsibility for their failures and avoid playing the "blame game," using mistakes as opportunities to learn and grow.

- **Emotional Baggage** – Leaders effectively manage their emotional baggage and the emotional baggage of their employees.

Leadership Styles In Action

Reflect upon the 3 styles as they relate to the role of the QIDP.

1. Give four reasons that an autocratic leadership style is not effective for a QIDP.

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2. List four specific ways that a QIDP can use democratic leadership.

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3. What do you think is the difference between delegation and a delegative leadership style?

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Frameworks of Leadership

More recent thinking, writing and study regarding leadership asserts that leadership, has more depth than Lewin's styles. Contemporary frameworks of leadership are often based upon character, interpersonal relationships and communication. Most assert that leadership is not about personality; it's about behavior. Leadership frameworks often identify a set of skills and abilities that can be studied, learned and applied contingent upon context.

One way to think about leadership and your role as a QIDP is:

- Leadership of self
- Leadership of others

Leadership of Self

Leadership of self is about taking personal responsibility for your decisions, choices and actions. It is about taking responsibility for both what we do and what we don't do.

Challenges are seen as opportunities, not as burdens that prevent our success. Personal responsibility is about refusing to be a victim of life happening to us.

Stephen Covey, author of *First Things First*, *The 7 Habits of Highly Effective People* and *The 8th Habit*, defines character as the "sum of habits" and therefore, to become successful or to be a leader, you need to cultivate the necessary habits. He suggests that highly effective people share these principles. His foundational habit, Habit 1, is "Be Proactive." Habit 1 is about personal responsibility and begins with the mindset "I am responsible for me, and I can choose."

Self-leadership is thus the starting point recognizing, as Stephen Covey would say, "We all carry our weather with us".

Leadership of Others

Your particular position may or may not include the management and supervision of others. Nevertheless you will often be responsible for the behavior of others, making your capacity to influence and inspire even more important.

Robert Greenleaf, author of *Servant Leadership,* states, "The servant-leader is servant first. It begins with the natural feeling that one wants to serve. Then conscious choice brings one to aspire to lead. The best test is: do those served grow as persons; do they, while being served, become healthier, wiser, freer, more autonomous, more likely themselves to become servants?"(Greenleaf, 1977/2002, p. 27)

The people we serve grow and learn largely because of the day to day interactions that they have with DSPs, not because of perfect service plans written by QIDPs. This makes your interactions and your relationships with the DSPs incredibly important.

Having a genuine concern for the needs of others and recognizing such needs, as well as responding to them are hallmarks of servant leadership. It is not the loudest or proudest that is the leader, but the one who is in the service of others that becomes the true leader.

Personal Values are the principles, qualities, or standards that are considered worthwhile or desirable by a person. Thus, values describe what is important to a person. Your values are the result of all that you have experienced in your life and include influences from your parents and family, your religious affiliation, your friends and peers, your education, your reading, and more.

Values provide an internal compass and a rationale for a person's behavior. They represent your highest priorities and deeply held driving forces. Thus, values shape people's behavior. One of the easiest ways to determine a person's values is to watch how he or she behaves.

Effective leaders recognize these influences and identify and develop a clear, concise and meaningful set of values/beliefs. When you are part of any organization, you bring your deeply held values and beliefs to the organization. There they co-mingle with those of the other members of the company to create an organization or family.

Discuss your agency's core values.

Walking the Talk

Activity Description: Great leaders have identified and clarified their core working values. They understand how each of their core values translates into leadership behavior. Either working individually or in pairs, identify behaviors that exemplify the listed values.

Leadership Values	**How do you exemplify this value: habits, behaviors, etc.**
Integrity	
Positive Attitude	
Discretionary Effort	
Accountability	
Honesty	
Compassion	
Respect	
Stewardship	

COMMUNICATION

"The single biggest problem in communication

is the illusion that it has taken place."

— George Bernard Shaw

Why is communication important to you, as a QIDP?

Much of your job will be accomplished through communication with others, both verbal and written. The nature of the position requires that you talk to medical and clinical professionals, parents and family members, direct support staff and most importantly to the individuals you are supporting.

Understanding the tenets of excellent communication, knowing your personal style, recognizing others' style and being able to adapt will help you to build and maintain strong relationships. Effective communication is necessary for effective leadership.

Myths about Communication

1. **Focus on the Facts**: While facts are important, they cannot be the only focus of conversation. Often we spend too much time figuring out what to communicate and too little time on how to communicate. Communication is as much about the people communicating as it is about the content.

2. **Stick to the Truth**: Speaking the blunt truth without concern for the receiver, the situation and the context will not increase the likelihood that you are understood. When communicating, there are more options than honesty or dishonesty.

3. **Sugarcoat Bad or Unwanted Information**: Avoiding difficult conversations will neither eliminate the need for them nor facilitate strong relationships. Deliver your message respectfully. You can be considerate of the other person's feelings or vantage without sugarcoating.

Types of Communication

Communication between people occurs across three dimensions:

- Nonverbal Communication- Behavior and elements of speech (aside from the words themselves) that transmits meaning.
- Verbal Communication- The words that we choose
- Written Communication- Setting pen to paper

Nonverbal communication

The following are components of nonverbal communication:

- Facial expression
- Gestures
- Body language or posture
- Manner of speech (sometimes called *para-verbal* communication). Manner of speech includes:
    - Tone- The general quality or character of the communication
    - Volume- Reflects the loudness of the communication
    - Cadence- The rhythm of the communication

The way you listen, look, move and react tells the other person whether or not you care, if you're being truthful and how well you're listening. When your nonverbal signals match up with the words you're saying, they increase trust, clarity and rapport. When they don't, they generate tension, mistrust and confusion.

Nonverbal communication is comprised of our facial expressions, gestures, and posture. It also includes the manner in which we speak: tone of voice, loudness and the rhythm of speech.

Facial expressions are among the most universal forms of body language. The expressions used to convey fear, anger, sadness, and happiness are similar throughout the world.

We use gestures to express ourselves often without thinking. We may use our hands when arguing or speaking animatedly. Gestures can be either intentional and direct or unintentional. Gestures change considerably across cultures, so it's important to be careful to avoid misrepresenting your message.

The position of our bodies or parts of our bodies is referred to as posture. Posture can convey a wealth of information about how a person is feeling as well as hints about personality characteristics, such as whether a person is confident, open, or passive.

The tone of voice we use is also an important part of nonverbal communication. We've often heard the phrase "It's not just what you say; it's **how** you say it." People can 'read' our voices by listening to timing and cadence, loudness and tones and inflection. For example, tone of voice can indicate sarcasm, anger, affection or confidence.

Nonverbal communication can be in alignment with or contrary to what is being said.

Verbal Communication

Words not only convey information, they also mirror our values. As a professional, the QIDP can convey a sense of respect or lack of it by the words that are chosen when communicating with individuals supported or colleagues. Whether speaking or writing, it is important to choose just the right words to convey your message. You may need to change the wording that you use depending on who the receiver of your message may be. Always remember to use respectful, people first language when communicating about individuals supported.

A Word About Noise

Noise is defined, in communication terms, as anything that interferes with the communication process between a speaker and his/her audience. It can be internal or external and can disrupt communication at any time.

There are four categories of noise; **physiological, physical, psychological**, and **semantic**.

Physiological noise is created by what we think and how we feel. Being hungry, tired, angry, anxious, feeling ill, or actually having blindness or deafness are internal conditions that can affect what we say and hear, causing messages not to be received as they were intended.

Physical noise could be an airplane passing overhead, a classroom full of chatty teenagers, the hum of the refrigerator, air temperature that is too hot or cold, lighting that is too bright or dim, or the feedback from a microphone. In addition, conditions such as standing next to the speaker system or trying to conduct a meeting with construction being done on the building next door can interfere with the way a message is received.

Thoughts of not being good enough, interesting enough, or engaging enough for the audience can interfere with one's ability to clearly encode the message in a public speech. **Psychological noise** includes cultural bias, prejudice, being defensive or sad. Another source of psychological noise might be having a disorder such as Autism. Any of these things can distort a message.

Telling a joke with a punch line that is specific to a geographical area, using local jargon or professional terminology are examples of **semantic noise**. A speaker whose native language differs from the listener's may have trouble sending clear messages. Heavily accented speech often has the same effect.

Word Choice – QIDPs work with a wide variety of people. Understanding that your choice of words may need to be significantly different from person to person will make **you a more effective communicator.**

Discuss how you might give the same information to a parent, a doctor, and a DSP. How might your word choices change in each of the conversations?

Tone – Your tone is as perceived by the person you are talking to. In other words, if the listener feels that your tone is sarcastic, professional, upbeat or offensive then that is the quality of your tone, regardless of whether that was your intention.

A great deal of humor is based upon sarcasm. Discuss why sarcasm may be problematic when communicating with the people we serve.

Volume – Most people have a sense of their natural volume. Are you a loud talker or a mumbler? Matching your volume to that of the person you are speaking to can be helpful.

Sometimes we raise our voice without realizing we are doing it. Discuss some situations where you unknowingly raise your voice without realizing it.

Cadence - The rhythm and speed of your speaking can have a big impact on the listener's understanding and processing of the message. In circumstances where you are not understood, it may not be your word choice, but the speed at which your message is being delivered.

Discuss situations in which the cadence and speed of your speech affect how a message is heard by the listener.

Noise - Working to reduce the noise involved in communication, based on your audience, is important to making communication more clear.

Consider the noise conveyed by a large man with a very deep tone. How might stature and appearance affect the way a message is heard and processed?

Considering the concept of noise when communicating with individuals with disabilities is crucial to the success of the communication process. Discuss why noise may be problematic when communicating with the individuals we serve.

Written Communication

Written communication differs significantly from verbal and nonverbal in that there is a permanent product. Written communication does not have the benefit of supporting communication such as facial expressions, tone, volume and cadence.

When determining the best way to send a message, consider the following:

- The sensitivity and emotional content of the subject
- How easy it is to communicate detail
- The receiver's preferences
- Time constraints

A Word about E-mail:

Recognizing that we live in a world where virtually everyone is connected to the internet, it is becoming more common for professional correspondence to occur through email. Because your conversation is in writing, both you and the email recipient are unable to use visual and auditory cues to help interpret meaning. Word choices are more crucial in such situations.

It is important to use email etiquette each time you send a message in order to effectively communicate with others. Here are a few tips to remember before you send an email:

- Use the subject line and be descriptive with it. This makes your search, or someone else’s search, for the email later on *much* easier.
- Address the person at the beginning of the email. For example, “Hello Linda.”
- Consider opening with friendly dialog rather than jumping right to the subject to avoid appearing curt.
- Be clear and concise.
- The use of symbols and graphics are not appropriate or professional (e.g. smiley faces).
- Be careful with the use of all caps and bolded words, some find it offensive.
- Choose your words carefully. Avoid anything the reader could perceive as sarcasm or negativity.
- Stick to non-emotional, factual statements. Avoid voicing your opinion unless it’s particularly relevant; don’t editorialize.
- Close the email with a professional phrase such as “Sincerely” or “Regards.”
- Add a signature line with your contact information to every email.
- Read through your message before sending.

It is important to recognize both when to send emails, as well as when to “stop the email chain” and pick up the phone. Can you think of specific examples of when this may be true for a QIDP?

Insert agency specific email information here.

A Note about Professional Phone Messages: Often you will be relying upon connecting with people via the telephone and you are not likely to be behind a desk for much of the day. Given this, you may find yourself periodically in a game of phone tag, where you and another person call regularly but rely upon messages. When taking or leaving a message consider the following:

- When leaving a message, spell names and recite numbers slowly enough for the listener to write them.
- You might ask that the information be repeated back to you
- Providing information about the purpose of your call will help the person be more prepared when they return your call.
- When taking a message, ask for names to be spelled or numbers to be repeated
- You might ask if the recipient is expecting the call
- Requesting information about the purpose of the call will help the person be more prepared when returning the call.

Insert agency specific phone information here.

Opportunities for Effective Communication

While working as a QIDP, you will have numerous opportunities for communicating and linking with others. Look over the following chart and identify potential barriers to effective communication with the identified parties, noting solutions you may have identified from the material covered thus far.

Who	What are you likely to talk about with this group?	Considerations When Communicating *Barriers / Solutions*
Individual (Client)		
Family Members		
Direct Service/ Support Staff		
Other Agencies, Other Providers		

DiSC: A Framework for Communication

The success of communication is the responsibility of the communicator. Through flexibility, the communicator should adapt his or her style to the style of the person with whom they are communicating. Although each style has its strengths and challenges, with none in particular being superior to the rest, learning to communicate with each style is crucial to creating and maintaining a healthy relationship.

One Personality Profile called the DiSC is based on the work of psychologist Dr. William Moulton Marston and was introduced in his 1928 book "Emotions of Normal People".
The DiSC Framework outlines four main styles of communication. Although we are all a combination of all four styles, we may rely more heavily on one style in comparison to the others.

The Dominant ***D*** Style focuses on results. Guided by big rewards, they enjoy determining what can be accomplished. The Dominant style is easy to spot because they just want the facts and nothing but the facts. Because of this, many times they can be perceived as bossy and insensitive. They are extremely goal oriented and their major motivation is to get things done. They'll take a project and run with it. Many times they won't even have a plan when they begin. They'll just forge ahead with an attitude of "we'll figure it out as we go." The Dominant style paints with a broad brush and has little use for details, so don't give them any more details than are absolutely necessary to get your point across.

An Influential ***I*** places emphasis on others. They are often very social, warm and trusting individuals. They love people and love to talk. Their natural sociability allows them to talk for long periods of time about almost anything. They have an attractive personality and are the life of the party. They are enthusiastic, curious, and expressive.

The Supportive ***S*** individuals minimize conflicts to create a calm, compassionate environment. They are patient, well-balanced, and make up the largest percentage of the population. The person with a Supportive communication style typically has a low key personality and is calm, cool and collected. They tend to be patient, well balanced and happily reconciled with life. Supporters are the largest percentage of the population and they are typically competent and steady workers who do not like to be involved in conflict. When there is conflict they may be called upon to mediate the problem. They are good listeners and usually have many friends. One of their major motivations is to avoid offending anyone.

The detail-oriented Conscientious ***C*** values accuracy and details. Please the C with lists, charts, graphs, and figures. These are the "facts and figures" people. They love to gather details and organize things. They tend to be deep, thoughtful, analytical, serious and purposeful. Because their communication style includes a need for details, they sometimes hesitate to make decisions if they feel that they don't have enough facts. They love lists, charts, graphs and figures. Because they pay so much attention to details, they can sometime be seen as being pessimistic. Many times they can be seen as frugal or economical.

DiSC Communication Styles

The information in the DiSC chart further describes each of the DiSC styles. As you read, identify which type of communicator you believe you are. Think of the people you communicate with on a daily basis, what style are they? Have you been communicating with them properly?

Outgoing

Task Oriented

People Oriented

D- Styles

Identification

- Decisive, tough, impatient
- Strong-willed, competitive
- Demanding, independent
- Direct, does not listen

Communication

- Be direct, brief and to the point
- Focus on the task, stick to business
- Use a results-oriented approach
- Provide win/win situations
- Tough on high points, do not over use data

i-Styles

Identification

- Sociable, talkative, open
- Enthusiastic, energetic
- Persuasive, spontaneous, impulsive
- Emotional, talks more than listens

Communication

- Allow time for socialization
- Lighten up; have fun
- Ask for feelings and opinions
- Expect quick decisions
- Provide opportunities for recognition and reward

S-Styles

Identification

- Calm, steady, laid back
- Careful, patient, amiable
- Listens carefully, sincere
- Modest, indecisive, trustworthy

Communication

- Be patient
- Draw out his/her opinions
- Provide a logical approach to the facts
- Relax; allow time for discussion
- Show how solutions will benefit

C-Styles

Identification

- Precise, exact, analytical
- Logical, systematic
- Quiet, does not express emotion
- Careful, formal, disciplined

Communication

- Use data and facts
- Examine an argument from all sides
- Focus on quality
- Avoid new solutions; stick to proven ideas
- Keep on task, do not socialize

Reserved

Communicating Using DiSC

Reflect upon the following statements as they relate to the role of the QIDP.

1. How would you communicate with an individual you help support if you knew he/she was a D?

   ____

   ____

   ____

   ____

2. Suppose you determined that you were leading a group of S's? What are four things you should NOT do in your group meeting?

   ____

   ____

   ____

   ____

3. If you are on the phone with an individual's guardian, whom you knew to be a C, how might you communicate the need for the individual to switch day programs?

   ____

   ____

   ____

   ____

4. You have identified your boss as an I communicator. How would you provide feedback to your boss on a specific program he/she just asked you to review?

   ____

   ____

   ____

   ____

5. What style communicator are you? How do you know?

   ____

   ____

   ____

   ____

Facilitating Effective Meetings with Leadership and Communication Skills

You will attend many meetings and will facilitate even more. Examples of types of meetings are:

- Staff/Department
- Annual staffing/CST
- Meeting with families and other providers
- Special projects
- Intake
- Service planning

Although each meeting has a different purpose and agenda, they all have the same basic structure. Each has a beginning, middle, and end. At the beginning you set the tone and direction; you create roles and ground rules to guide participant behavior. In the middle, you discuss the agenda and at the end, you confirm agreement regarding necessary actions.

Recognizing your role as both leader and facilitator will assist in maximizing the productivity and experience of the meeting for everyone.

Preparation Sets the Stage

- Choose a time and place conducive to the purpose of the meeting
- Provide meeting time and place to the participants
- Make the purpose of the meeting clear to all members
- Prepare agenda prior to the meeting
- Provide team members with an opportunity to contribute to the agenda
- Confirm attendance of participants

Conducting the Meeting Takes Focus

Setting the Tone

To facilitate an effective meeting, it is important to ensure that everyone understands the purpose, scope and limitations of the meeting.

Introductions are important, even if you think that everyone knows everyone else. Introductions will minimize awkwardness for people who may recognize others but not remember their name.

- Start on time
- Review the agenda or plan for the meeting
- Explain “rules”
- Encourage participation and be prepared to lead the discussion
- Be flexible but stay focused

Reaching Consensus

Although meetings occur for many reasons, virtually every meeting involves decision making and agreement among participates.

Consensus encourages the team to focus and work together. It is the voluntary giving of consent. It involves the group's 100% support for a decision or position even if not all members totally agree with the position. The QIDPs role involves helping the group achieve consensus.

The following are ways to facilitate consensus:

- Make sure adequate time is given to an issue
- Recognize that disagreement may be a part of the process
- Encourage negotiation and collaboration between team members
- Emphasize fact not opinion
- Use structured decision making tools
- Emphasize that compromise doesn't necessarily equate to loss
- Voting is not a viable alternative to sharing information, debating points, providing data, and exploring other alternatives

Summarizing Ensures that Everyone Leaves on the Same Page

- Bring closure to the discussion
- Move to action/seek commitment

Barriers to Effective Meetings

Barrier	Description
Professional Jargon	Members do not understand the clinical terminology. Keep it simple and understandable.
Getting off Topic	An issue may come up that is "bigger" than the one being discussed and the focus inadvertently switches. Ask the group to return to the topic-at-hand.
Side Conversations	Side conversations should be kept to a minimum; they slow progress and limit individual contributions. Use non-verbal communication (raise eyebrows), ask a question, or verbally intervene to put an end to the issue.
Timing	Be it starting late or running too long, be sure to keep an eye on time. Give adequate breaks. Members need reminders and choices to obtain closure.
Repetitive Conversations	Recounting old topics or old stories can cause other participants to mentally check out. Redirect the members to get back on task.

SCENARIOS

Discuss the following scenarios. How would you handle each situation?

Scenario 1: In your monthly meeting, your team has been discussing the same topic for far too long. You're running out of time and have more to cover. How should you handle this situation?

Scenario 2: It's 10:00 a.m. and your meeting is supposed to start, but one of your employees is late. What should you do? Do you say anything to them at the time that they arrive?

Scenario 3: In a Service Plan meeting, an individual's mother states that she is upset about the way her son is being treated at the CILA. He apparently is feeling bullied by housemates and spends the majority of his time in his room. As the QIDP, how would you respond to this situation?

Other Difficult Meeting Scenarios to Discuss:

- Someone who makes a good point, but one that is not related to the topic
- Someone who makes an irrelevant, unworkable suggestion
- Someone who whispers or writes notes to others throughout the meeting

Recommended Reading & Resources

Although we will try to cover a great deal of material with you today in class, the topic of leadership and communication is a broad one that requires continued study and attention throughout your career. We recommend the following resources as good places to start with regard to furthering your knowledge and understanding of this important topic.

- The 7 Habits of Highly Effective People by *Stephen Covey*
- The 8th Habit: From Effectiveness to Greatness by *Stephen Covey*
- The 21 Irrefutable Laws of Leadership: Follow Them and People Will Follow You by *John C. Maxwell*
- The Agile Manager's Guide to Leadership by *Walter J. Wadsworth*
- Bringing Out the Best in People by *Aubrey C. Daniels*
- Developing Staff Competencies for Supporting People with Developmental Disabilities (Chapters 6,15, & 18) by *James F. Gardner and Michael S. Chapman*
- Handbook of Leadership: A Survey of Theory and Research by *R.M. Stogdill*
- Leadership Styles by *Donald Clark* http://www.nwlink.com/~donclark/leader/leadstl.html
- Managing Disagreement Constructively: Conflict Management in Organizations by *Herbert S. Kindler*
- Meetings that Work by *Marlene Caroselli, Ed. D*
- The New Supervisor: Skills for Success by *Bruce B. Tepper*
- Patterns of Aggressive Behavior in Experimentally Created Social Climates by *Lewin, K., Llippit, R., White, R.K.*
- Reality-Based Leadership: Ditch the Drama, Restore Sanity to the Workplace, and Excuses Into Results by *Cy Wakeman*
- Servant Leadership: A Journey Into the Nature of Legitimate Power and Greatness by *Robert Greenleaf*

- Taking Flight!: Master the DISC Styles to Transform Your Career, Your Relationships, Your Life by *Merrick Rosenberg and Daniel Silvert*

- Team Building: An Exercise in Leadership by *Robert B. Maddux*

- Why Employees Don't Do What They're Supposed To Do..and What To Do About It by *Ferdinand F. Fournies*

Appendix A

A Meeting Checklist

Before The Meeting

__Choose a time and place conducive to the purpose of the meeting

__Agenda is prepared prior to the meeting

__The purpose of the meeting is clear to all members

__Team members have an opportunity to contribute to the agenda

__Meeting time and place are provided to the participants

__Meeting place is comfortable

__Confirm attendance of participants

During the Meeting

__Meeting begins on time

__Introductions are given, even between those who know each other

__Review agenda and purpose

__Use of time is monitored throughout the meeting

__Each member has an opportunity to present his point of view

__Encourage participation and be sure to offer each participant an opportunity to speak

__Members listen carefully to each other

__Be flexible, but stay focused

__Meeting summaries are given periodically throughout the meeting

__No one dominates the discussion

__Everyone has a voice in decision making

__Bring closure to the discussion; Meeting ends with a summary of accomplishments

__People are identified to carry out the action they agreed upon

After the Meeting

__A summary is provided to all members after the meeting

__The QIDP follows up with the members on action agreed upon

Appendix B

Don’t Dictate...Facilitate:
How to Gain Consensus without Being a Tyrant

by Diane DiResta, for *Winning Team*

Do discussions you’re leading shut down when you’re hoping they will open up? Is one person always dominating meetings? Do team members not in agreement sabotage your efforts? Chances are you’re contributing to the meltdown. Here are a few reasons why team members crash and burn in team meetings.

The team leader talks too much. Lecturing leads to some of the lowest levels of learning and retention. People can easily tune out. According to adult learning research, adults want a sense of control. When the leader does most of the reporting or speaking, the team does not feel involved and will not buy into new ideas so readily. Sell, don’t tell.

Team members don’t listen. Even if the team leader is listening, others may not be. Is the role of the leader to facilitate the discussion so that others can be heard? Members may talk over one another, take credit for someone else’s idea, or discredit a person’s suggestions. These behaviors demonstrate a failure to listen. When people aren’t heard, they don’t feel respected. Without respect, the members won’t support each other.

One member dominates. This can happen when the team leader gives one person the floor. More often, it’s a result of a strong personality with unmet needs. He or she can intimidate others. The challenge for the team leader is to meet the needs of the dominating person while encouraging others to contribute.

A facilitator orchestrates but does not take center stage. The focus is on the team. This requires a change of mindset. Many leaders fall back on lecturing, telling, and instructing instead of coordinating and facilitating. It’s easier to do what’s familiar. And some leaders believe to facilitate is to give up control.

Why facilitate? Team members feel heard and respected. This increases morale. More ideas are captured for greater innovation and productivity. Mistakes, glitches and weak strategies are identified, reducing costly errors. Leaders earn support and commitment when the team “owns” the idea. Finally, work is more fun when everybody feels important.

Good facilitators do the following:

Speak less and listen more. Be clear about your objective. If your objective is to get ideas from the group or to gain support for a new initiative, state the purpose, ask questions, and listen. To facilitate a meeting effectively, speak 20% of the time and listen 80% of the time.

Keep the discussion on track. Your job is to make sure that the major points are covered through discussion. A good facilitator preplans the time for each agenda item but is flexible enough to depart from the agenda. The challenge is to know when to rein in the discussion without turning people off. Facilitation is like fishing with a net. You let out the net far enough to catch the fish—the fish swim into the net.

QIDP Professional TRAINING

Illinois Department of Human Services

Module 1: Introduction to the World of the QIDP
Module 2: Leadership and Communication
Module 3: Behavioral Supports
Module 4: Person Centered Planning
Module 5: Record Keeping
Module 6: Advocacy, Rights, and Resources
Module 7: Environmental and Safety Supports
Module 8: Medical Supports
Module 9: Rules and Regulations

Module Overview

Module 3 Introduction

Why this information is relevant to you, as a QIDP?

As a QIDP you will sometimes find pressure to “fix” problem behavior. In fact, many people with intellectual and developmental disabilities have a history of others trying to “fix” them. Instead, it is more helpful to support the individual in areas where they would like to change. Challenging behavior can be draining to staff, an obstacle to learning, and limit a person’s ability to make and keep friends. Understanding behavioral supports will assist you with thoughtful planning when addressing challenging behaviors and, at the same time, promote dignity, ownership and most likely lead to a successful outcome.

Objectives

Participants will be able to:

- Discuss four factors that affect behavior.
- Describe behavior in observable terms.
- Define adaptive vs. maladaptive behaviors.
- Conduct staff interviews for the purpose of understanding behavior.
- Differentiate between frequency, duration and latency.
- Identify A-B-C contingencies.
- Discuss four functions of behavior.
- Define reinforcement.
- Define extinction.
- Define differential reinforcement.
- Assist with the development of a behavior support plan.
- Use agency data collection forms.
- Identify agency behavioral support resources such as committees and Behavior Analysts.

UNDERSTANDING BEHAVIOR

> *"People do what they do because of what happens to them when they do it."*
>
> **-Aubrey Daniels**

Behavior can be simply defined as "anything a person does". All observable actions are included. Whether a particular behavior is considered adaptive or challenging is largely a function of the person, place and circumstance. Behavior that is common and acceptable at a ball park is not acceptable in a grocery store.

Some behavior is adaptive and other is maladaptive or sometimes called non-adaptive. Adaptive behavior is the collection of conceptual, social and practical skills that have been learned by people in order to function in their everyday lives. They may sometimes be called *life skills*. These important skills enable us to live in a safe and socially responsible manner. Significant limitations in adaptive behavior impact a person's daily life and affect his/her ability to respond to a particular situation or to the environment.

All behavior has a purpose and serves a function. Many factors come into play when understanding behavior.

- A person's history
- Strengths and limitations
- Related conditions: psychiatric and medical
- Environmental

A Person's history

Much of what we do today, our patterns of behavior, is in large part tied to our past experiences. Examples of relevant historical factors include family structure, education, work and relationships.

Discuss the possible impact of the following events in a person's life:

Death of a loved one
Abuse/neglect
Institutionalization
Living with parents until 50 years old

Strengths and Limitations

A person's strengths and limitations are likely to be a big factor in their day to day behavior. Strengths can be every day skills or skills that we have worked very hard to acquire. Our limitations might be clear and known to us or perhaps unrecognized by us but seen by others.

How might the following strengths affect the person's behavior today?

- Excellent memory
- Fine motor skills
- Reading
- Active and high energy

How might the following challenges affect the person's behavior today?

- Difficulty walking
- Confusion
- Limited language
- Sensitivity to loud noises

Related Conditions

Psychiatric and medical conditions can seriously impact a person's ability to do even the simplest of tasks.

Discuss the possible effects that the following psychiatric/medical conditions:

- Obsessive compulsive disorder
- Schizophrenia
- Depression
- Anxiety disorders
- Diabetes
- Seizures
- Poor dental care
- Constipation

How might acute or chronic pain play a role in the following behaviors?

- Head banging
- Throwing Food
- Pacing in the middle of the night

Environmental Factors

What one person finds exciting and stimulating, another may find annoying and abrasive. Often environmental factors such as temperature, noise, level of activity and pace impact a person's behavior.

Discuss the following situations, the challenging behaviors that might arise during them and the particular factors that might be at play.

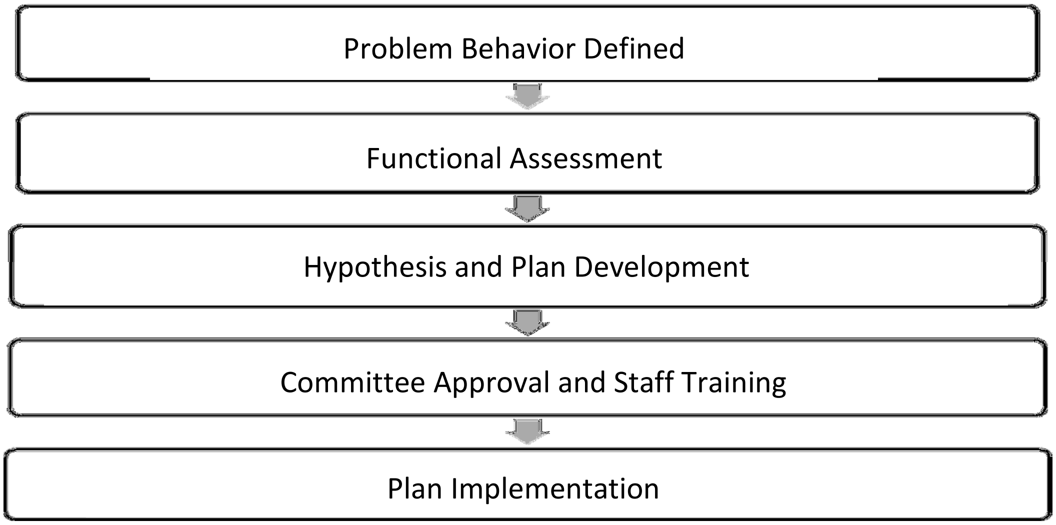
- Standing in line
- Watching TV
- Grocery Shopping
- Riding in van in morning
- Dinner time
- Cleaning House

Preventing and Minimizing Challenging Behaviors

The intent of this module is to familiarize you with basic behavior assessment and simple behavior support plans so that you are better able to support a person's day to day needs. It is beyond the scope of this module to teach you enough about behavioral supports for you to move forward addressing complex challenging behaviors without additional support.

Insert information about your agency's behavioral support resources for new QIDPs.

The flowchart below is one way to conceptualize the flow for behavioral supports.



Defining Behavior

Common terms used interchangeably with behavior include activity, action and performance. Terms such as reliable, competent, trustworthy and energetic might be used to describe an employee but do not provide information about specific behaviors. What is it that the employee does that makes them reliable? Reliable for one person might be perfect attendance, while reliable for another might mean that they always have a "good" reason to be absent.

Agreement on behavior definition is particularly important for successful behavior reduction. When describing challenging behavior we sometimes say "He hits his coworkers" or "He always screams". While both offer a bit more information than "he is always angry", to effectively decrease that behavior more detail is necessary. A better definition allows for multiple people to agree that the behavior occurred. For example: "Hitting self with open hand with sufficient force to produce bruising on the face or head."

Defining Behavior in Observable Terms

Rewrite the phrases below so that they become observable behaviors.

Jenny is not a good worker.

Tom talks too much.

Jeremy is impulsive.

Martha is unsafe.

Debi is a bully.

Steve does inappropriate things in public.

Functional Behavioral Assessment

Functional behavioral assessment is used to better understand a person's behavior and to identify the function of the behavior. The process involves collecting information through the use of direct observations, interviews, and record reviews. The information gathered is used to identify patterns of behavior, the antecedents (what comes immediately before) and consequences (what comes immediately after) the target behavior.

A functional behavioral assessment attempts to identify the ABCs of behavior. ABC stands for:
A*ntecedents* – the events/situations that have led up to the behavior's occurrence.
Behavior- the specific behavior you are trying to increase or decrease.
C*onsequences* – what happens after the behavior occurs.

Interviews as a Means of Collecting Information

Often interviewing those who work directly with or live with the person is the first step in trying to understand behavior. Questions might include:

1. What do you think causes the behavior?
2. What happens just before the behavior occurs?
3. Are there any circumstances when the behavior does not occur?
4. Describe the behavior of concern. (Use observable & measurable terms)
5. How often does the behavior occur?
6. How long does it last?
7. How intense is the behavior?
8. What is happening when the behavior occurs?
9. When/where is the behavior most/least likely to occur?
10. With whom is the behavior most/least likely to occur?
11. What conditions are most likely to precipitate ("set off") the behavior?
12. Does language play a factor in this? Please explain your answer.
13. How can you tell the behavior is about to start?
14. What usually happens AFTER the behavior?
15. What is the likely function (intent) of the behavior, that is, why do you think the individual behaves this way? What does he/she get or avoid?
16. What behavior(s) might serve the same function (see question 9) for the individual that is appropriate within the social/environmental context?

Direct Observation

The three most used dimensions of behavior are: frequency, duration and latency.
Frequency refers to the number of instances that a behavior occurs over a specified period of time.

Example: Number of times person washes hands
Advantages: Relatively simple to use
Disadvantages: Not appropriate for continuous behavior, difficult for high rate behaviors

Duration refers to the amount of time from the time of onset to the termination of behavior.
Example: Number of minutes a person exercises
Advantages: Appropriate for behavior that occurs over time
Disadvantages: Requires a means to record passage of time

Latency refers to the amount of time between the cue for behavior and the onset of behavior.
Example: Amount of time between alarm and getting out of bed
Advantages: Appropriate for assessing delays of response
Disadvantages: Difficult to measure, and requires a means to record passage of time

Recording of Behavior

Continuous Recording attempts to record every instance of behavior over a given period of time. It can be labor intensive.

Interval Recording involves observing whether a behavior occurs or does not occur during specified time periods. In this method, the observer periodically looks at the person at predetermined (NOT spontaneously selected) intervals and records whether the behavior is occurring.

- In *whole interval* time sampling, you observe the person for a few seconds at designated intervals and notice whether the behavior occurs for the whole interval that you are looking for it (mark "yes" or "no" as to whether this behavior occurred for the whole time that you were watching).
- In *partial interval* recording, you mark whether the behavior occurred at least once during the short observation interval.
- In *momentary time sampling*, you look up immediately at pre-designated points and notice whether the behavior is occurring at that precise moment.

In all three types, the observer then figures the percent of observations that the behavior occurred. Interval recording is used for the same behaviors as duration recording, but this procedure takes less time and effort, and does not require that the individual be observed continually.

Antecedent-Behavior-Consequence

*Read each passage below. **U**nderline antecedents, circle challenging behavior and place a box around consequences.*

1. Billy has loved music since he was a small child. Every year his sister buys him CDs for his birthday. He is twenty-two years old and likes to go to concerts. Often he can be found wearing his headphones to listen to his iPOD. Mark, his roommate, pulled his earphones out of his ears. Billy hit Mark in the face with his iPOD. Mark yelled for staff and Billy went to his favorite chair to listen to his iPOD again.

2. Samantha's sister Grace is teasing her. Samantha leaves the room. Grace follows her but Samantha leaves the room again. Grace sneaks up on her from behind and says "Booo". Samantha pushes Grace and screams for their mom.

3. Fred is working on his homework and begins to encounter problems that are difficult for him to complete. Fred begins banging his head and yelling. His dad tells him to take a break from his homework.

4. Steve is in his room. He calls for his roommate, Bart to come listen to music with him. Bart is watching TV and ignores Steve. Steve continues to yell. Bart goes to Steve's room.

Developing a Hypothesis Statement

The purpose of functional assessment is to identify relationships between behavior and antecedents/consequences so that appropriate interventions can be developed. Listed below are a few common functions of behavior.

Escape/Avoidance of Tasks or Requests

- Does the behavior start when a request or demand is made?
- Does the behavior start when a particular person is nearby?
- Does the behavior stop when the individual is removed from the activity?

Discuss situations that might result in escape maintained behavior.

Obtain Attention/Tangibles

- Is the individual alone or unattended for long periods?
- Does the individual exhibit the behavior when he/she is alone?
- What is the reaction of staff when the behavior occurs?
- Does the behavior stop after the individual receives a desired object?

Discuss situations that might involve attention seeking behavior.

Communication

- Does the individual have a functional and reliable communication system?
- Is the individual provided with the necessary equipment/skills to communicate wants and needs?
- Do direct support staff utilize and understand the individual’s means of communication?

Discuss the relationship between poor communication and aggressive behaviors.

Alleviation of Pain

- Is it possible for the individual to be in pain?
- Does the person have any know medical issues?

What challenging behavior may be a result of an earache?
What challenging behavior might be a result of a stomach ache?

Self-Stimulation or Sensory Stimulation

- Does the individual repeat the behavior when alone?
- Does the individual appear unaware of his surroundings?
- Does the individual's behavior suggest a sensory component, such as shielding eyes from light, covering ears or removing clothing?

Why might it be extra difficult to decrease behaviors that are reinforced by sensory stimulation?

Replacement Skills

Once the purpose of a behavior has been determined, an alternative means for achieving the same purpose should be identified and taught. When selecting replacement skills, it is important to realize that the more efficient and effective the replacement skill, the more likely it will be used. Replacement skills should be taught often and consistently. Teaching replacement skills only at the time of challenging behavior is not likely to result in change.

Examples – Hypotheses	Replacement Skills
When a staff person's attention is withdrawn or focused on others, Charles makes noises; his behavior results in the staff person talking to him and moving closer to him.	
When unanticipated changes in the routine occur, Elisa throws her materials; having to pick them up delays the transition to the next activity.	
When Ben finishes an activity early, he bites his fingernails and cuticles; this gives him another form of stimulation.	

Reinforcement

Positive reinforcement is an event or a stimulus presented after a response that increases the likelihood that the same behavior will occur under the same circumstances in the future.

Factors Influencing the Effectiveness of Positive Reinforcement

1. A very specific definition of the target behavior will increase the likelihood that reinforcement is given consistently for the correct behavior.
2. Recognize that an object or an event is only a reinforcer when it increases the likelihood of behavior for that person. Reinforcers are highly individual.
3. The longer the deprivation period the more effective the reinforcer will be. If the person has access to the reinforcer without the behavioral contingency, the reinforcer will lose effectiveness.
4. For maximum effectiveness, the reinforcer should be given as close to the desired behavior as possible.

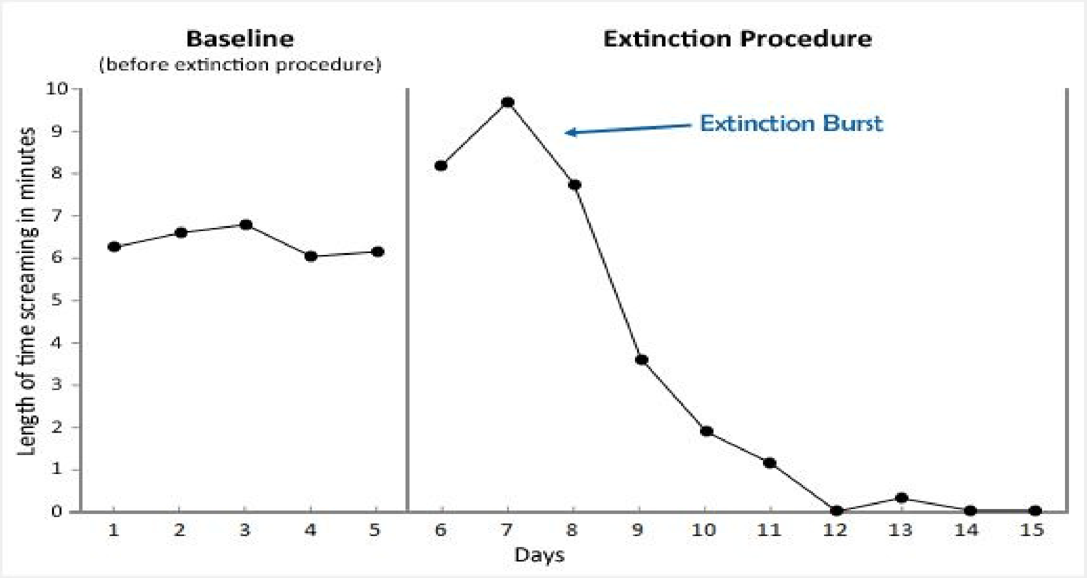
Extinction

Extinction is intentional withholding of reinforcement for a previously reinforced behavior. The principle of extinction states that if, in a given situation, a previously reinforced behavior occurs and is not followed by a reinforcer then that person is less likely to do the same thing again under similar circumstances. It is most often used with behavior maintained by attention.

Considerations for Extinction

1. Extinction is most often used when attention is the reinforcer maintaining the undesirable behavior.
2. Consistency among support staff is imperative in that periodic reinforcement of the undesirable behavior will only make the behavior stronger.
3. Some behaviors are too severe to use extinction.
4. Extinction is most effective when alternative behavior is taught.
5. Initially the challenging behavior may increase prior to decreasing. This is called an extinction burst.

Discuss the chart below. What would you, as a QIDP, do with this data?



Differential Reinforcement

Differential reinforcement can be used to decrease challenging behavior. It involves the intentional withholding of reinforcement (extinction) for the challenging behavior while reinforcing other more desirable behavior. The other behavior can be any other desirable behavior or a specified incompatible behavior. An incompatible behavior is a behavior that cannot be done at the same time as the challenging behavior. Spitting and humming are incompatible. Pacing and tapping your foot are incompatible.

Identify incompatible behaviors for those below:

- Pinching
- Scratching
- Rocking
- Hand mouthing

Review common data collection forms for your agency.

Understanding Kevin

Let's examine some data on Kevin. Kevin has recently begun having difficulties with yelling and swearing episodes and staff are trying to figure out why.

Over the next few pages, you will review behavioral data based on Kevin's daily activities. You will review his schedule and examine event tracking data (when maladaptive behavior has occurred). You will learn about scatter plots and use the scatter plot to plot Kevin's behavioral episodes over time. Finally, you will use the data to answer some questions about Kevin which will help in understanding his behavior over time.

Time:	**Activity:**	**Staff Person:**_____________
6:30 AM	Wake up housemates	Sally
7-8 AM	Breakfast	Sally
8 AM	Take bus to work	
9 AM to 1:30 PM	Work at Home Depot	Job Coach
2:30 PM	Arrive home on bus	Jon
3-3:30 PM	Other housemates arrive home	Jon and Dan
3:30-5 PM	Home chores	Jon
5-6 PM	Free Time	Dan
6-7 PM	Dinner	Jon and Dan
7-9 PM	(M, W, Th, F) Board games/social time	Jon and Dan with other housemates
7-9:30 PM	Going out to the community	Jon
9:30-11:00 PM	Relax, video games, etc.	Dan

***Weekend Schedule Changes:**
Kevin and other housemates sleep in and go out during the day

Event Tracking

Day/Date:	Time:	Activity/Behavior:
Mon 9/5	6:31 am	Screamed
	6:35 am	Screamed
	3:20 pm	Swore for five minutes
	6:50 pm	Screamed and swore
Tues 9/6	6:35 am	Screamed
Wed 9/7	6:40 am	Screamed
	3:25 pm	Swore for five minutes
	7:10 pm	Swore and screamed
Thur 9/8	6:35 am	Screamed
	3:29 pm	Swore for ten minutes
	7:45 pm	Screamed and swore
Fri 9/9	6:33 am	Screamed
	3:25 pm	Swore
	7:05 pm	Screamed and swore
Mon 9/12	6:32 am	Screamed
	3:25 pm	Swore for five minutes
	6:35 pm	Screamed
Tues 9/13	6:32 am	Screamed
Wed 9/14	6:32 am	Screamed
	3:31 pm	Swore
	6:44 pm	Screamed and swore
Thur 9/15	6:31 am	Screamed and yelled
	3:32 pm	Swore
	7:45 pm	Screamed and swore
Fri 9/16	6:34 am	Screamed
	3:25 pm	Swore
	7:20 pm	Screamed and swore

Scatter Plot

The scatter plot is another way to look at behavior. This simple tool takes little time and effort to complete but can yield valuable information.

After the data has been recorded for three to four weeks, a scatter plot can be used to identify patterns in behavior over time. This can help you identify when the behavior is more likely to occur, and then match those times and days to the activities, environments, task demands people and other events that may be triggering the behavior. It is also important to look for times when the behavior is least likely to occur so you can find out what things are working in the individual's life.

Some problem behaviors work well with a scatter plot. These include aggressive behavior toward others, screaming, ripping off clothing or breaking or hitting things. The scatter plot is not as useful with very high frequency behaviors; for example, any behavior that occurs an average of 10 or more times per hour.

The scatter plot has squares representing 30-minute intervals from 6:00 a.m. through 10:00 p.m., for a designated time period, usually three to four weeks. The person recording the data is asked to place an "X" in the square that corresponds to the time and date a challenging behavior occurs. The numbers which run across the top of the graph correspond to the date of the month. The time along the left side of the graph corresponds to the time of day that the behavior occurred. If a behavior occurs three or more times in 30 minutes, the whole square is darkened.

Look at the recorded data on Kevin's behavior of screaming/yelling and swearing. Transfer that information to the scatter plot. Then answer the questions that follow.

Scatter Plot

NAME________________________________ DATE:________________________________

BEHAVIOR DEFINITION:____

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23
6:00-6:30 a																							
6:30-7:00 a																							
7:00-7:30 a																							
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Understanding Kevin’s Data

Using information from Kevin’s daily schedule, data sheet and scatter plot, see if you can identify patterns about when the target behavior is most and least likely to occur.

1. What is different about weekday mornings (when there are problem behaviors recorded) and weekend mornings (no problem behaviors recorded)?

2. Why are Tuesday evenings (no problem behaviors recorded) different from the rest of the weekday evenings?

3. What is different about weekend activities and weekday evenings when there are problem behaviors?

4. Why do you think Kevin has no problem behaviors during the weekdays?

5. What minor changes would you make in Kevin’s schedule to help his day go more smoothly and possibly reduce some of his challenging behaviors?

The Behavior Support Plan

Developing a Behavior Support Plan

The behavior support plan is a written document that:

- Is developed, reviewed and approved by the individual and their team
- Is written specifically for the *individual* not the behavior
- Uses positive approaches
- Describes the behavior in objective and measureable terms
- Offers a hypothesis for the function and the context of the behavior
- Provides environmental and/or schedule modifications
- Provides replacement or alternative behaviors that meet the same needs as the target behavior
- Describes what and how to document

Building a Behavior Support Program

Behavioral supports should emphasize positive behavior practices and be provided with the dignity of the person as primary concern. It is our job to create environments and supports that make undesired behaviors irrelevant, ineffective or inefficient. In other words, we must help build lives that have meaning for each individual we help support. The goal is not to simply "stop the behavior", but also to improve the person's quality of life.

If the individual has difficulties with expressive and receptive language skills, it is important that an effective communication system is provided, if one does not currently exist. If a person is not able to communicate basic wants and needs, problem behavior(s) will likely persist or increase.

Environmental modifications must also be considered and included in the behavior plan. Environmental controls should provide a stable and predictable environment in order to prevent problem behaviors. The person's Support Team should consider these environmental considerations:

- Written and visual schedules are posted
- Visual supports are implemented
- Ample opportunities to exercise choice and control are given
- Access to abundant preferred activities and enjoyable interactions

Effective Behavior Support Plans:

- Are based on functional assessments
- Offer a hypothesis for the function and context of behavior
- Describe the challenging behavior(s) in objective and measurable terms
- Describe the desired behavior(s) in objective and measurable terms
- Are specific to the person, not the behavior
- Are based on the person's life goals
- Use positive interventions
- Assign who will implement the program

- Indicate what and how to document
- Reviews any risks of proposed interventions
- Are reviewed and approved by the person and/or guardian as applicable
- Describes success and when the plan needs revision

A Reminder About Restrictive Programs

There may be times when a restrictive program is implemented for the safety of an individual supported or those around the individual. It is important to remember that the restrictive program must first be approved by the agency Human Rights Committee (HRC) *before* it is implemented. Many times the QIDP will be the person presenting the information before the committee. In this case, be prepared and have knowledge of the following:

- Know the history behind the issue(s) under consideration.
- Know what has been tried before and what happened.
- Be sure you understand what is maintaining the behavior (attention, escape, etc).
- Submit data, preferably in graph form.
- Use the best available techniques.

The committee may also ask for the following:

- Functional Assessment of the target behavior for which the restrictive behavior is designed.
- Documentation that indicates the risks of the target behavior versus the risk of the proposed restrictive intervention.
- Efforts to replace the target behavior.
- Documentation that the behavioral support plan is reviewed regularly by the person's support team.
- Definition of the targeted behavior or behaviors.
- Informed consent from the individual or the individual's legal representative.

With any program that causes a restriction of rights, the following must be true:

- The restriction is *temporary.*
- The restriction is defined with *specific criteria* (under exactly what circumstances will it be used).
- The program is *paired with learning/training components* to assist the person in the eventual removal of the restriction.
- The restriction is *removed* upon reaching clearly defined objectives.
- The restriction is *reviewed* regularly by HRC.

Discuss Agency expectations with regards to behavioral support plans and HRC

Understanding Behavioral Data

Evaluating/Troubleshooting the Support Plan

Data from the behavior plan should be reviewed monthly, at a minimum, to determine whether the target behavior has decreased and the alternative behavior has increased. If the target behavior has not decreased or continues to increase, the team must re-evaluate the plan.

View and discuss redacted behavioral support plans with corresponding data from your Agency. Do you have standard format? Identify the necessary components of the plan. Is the plan as clear as it could be? Use the checklist below to help.

Yes	No	
		Is the behavior stated in specific, observable, and measurable terms? If no, restate the behavior using these terms.
		Does the behavior need to be measured differently? If yes, consider adding measures of intensity and/or duration or selecting a different method of data collection.
		Has the correct function of the behavior been identified? If no, revise the functional assessment.
		Is the intervention plan being implemented consistently? If no, remove the barriers that interfere with consistent implementation or develop strategies that can be implemented effectively.
		Can all staff demonstrate competency to implement the plan? If no, train staff or change staff schedule to include staff who can competently implement the plan.
		Is the individual still engaging in undesirable behavior that gives sensory stimulation? If yes, examine and address the individual's sensory needs.
		Is the individual communicating effectively? If no, provide communication strategies which the individual can access in all settings.
		Are cues and conditions in the environment structured in a way that triggers desired behaviors? If no, include antecedent control strategies in the intervention plan.
		Are reinforcers used consistently and do they actually increase the behaviors they follow? If no, develop an effective menu of reinforcers and use them consistently.
		Is the individual showing signs of increased agitation and anxiety since the implementation of the intervention? If yes, re-examine the demands being placed on the individual, making sure expectations are clear, and not too high or low. Make sure the intervention strategies are logical and meaningful to the person. Re-examine the interventions being used, making sure they are not harsh, unpredictable, illogical, or too difficult to implement.
		Has the plan been implemented long enough for the person to consistently connect the desirable behaviors with the reward contingencies on numerous occasions? If no, allow more time and opportunities for the person to experience the rewards that reinforce the desired behavior.

Recommended Reading & Resources

Although we will try to cover a great deal of material with you today in class, the topic of quality behavioral supports is a broad one that requires continued study and attention throughout your career. We recommend the following resources as good places to start with regard to furthering your knowledge and understanding of this important topic.

- Behavior Modification: What it is and How to Do it by *Garry Matin & Joseph Pear*

- Positive Behavior Supports for Adults with Disabilites in Employment, Community and Residential Settings by *Keith Story & Michal Post*

- Principles of Behavior by *Richard W Mallot*

- Trauma-Informed Behavioral Interventions: What Works and What Doesn’t by Karyn Harvey

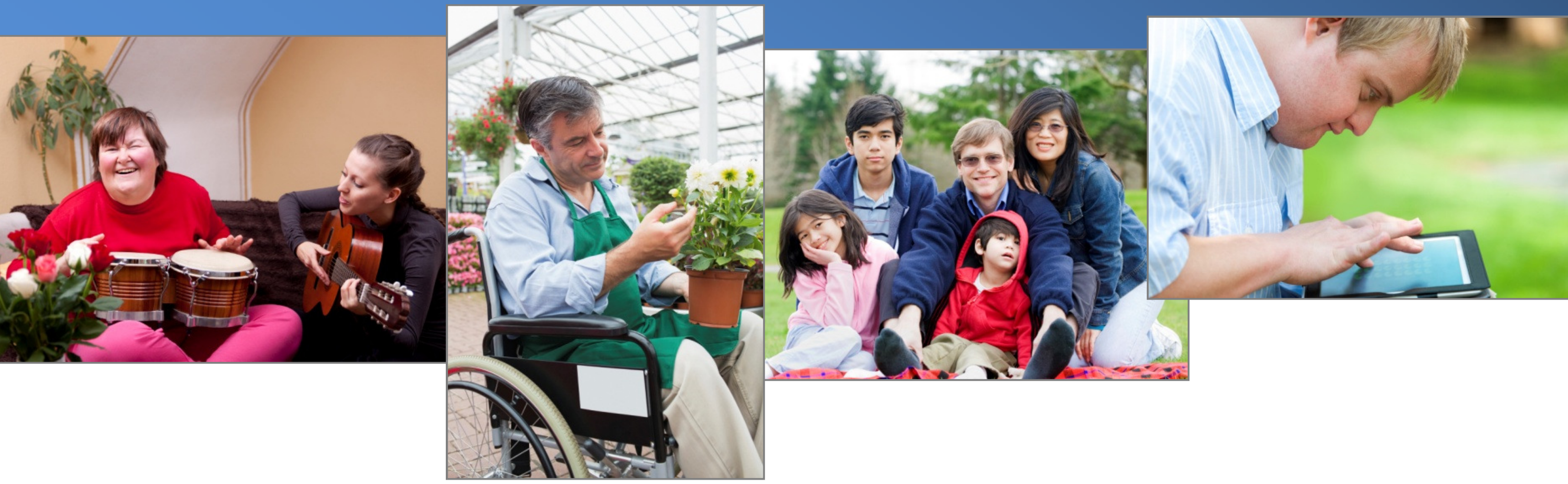
Supplemental Activity

Choose someone that you help support that has a behavior plan. Review the plan and answer these questions.

Individual's Name: **DOB:** **Date of Behavior Plan:**

ENVIRONMENTAL SET-UPS What things should be in place in this person's environment? What things should not be present in this person's environment?	
ANTECEDENTS What is likely to happen right before a problem behavior? What should you do if an event happens that usually comes right before a problem behavior? How can things be changed so the event does not occur?	
BEHAVIOR What are the problem behaviors to decrease? What are the appropriate behaviors to increase?	
CONSEQUENCES What should you do if the person does the problem behaviors that are to be decreased? What should you do if the person does the appropriate behaviors that are to be increased?	

QIDP Professional TRAINING



Illinois Department of Human Services

Module 1: Introduction to the World of the QIDP
Module 2: Leadership and Communication
Module 3: Behavioral Supports
Module 4: Person Centered Planning
Module 5: Record Keeping
Module 6: Advocacy, Rights, and Resources
Module 7: Environmental and Safety Supports
Module 8: Medical Supports
Module 9: Rules and Regulations

Module Overview

Module 4 Introduction

Why this information is relevant to you, as a QIDP?

As a QIDP, you are responsible for facilitating Person Centered Planning, which is to say that you are the person who will need to maximize the voice of the person you are supporting and minimize the team's tendency to focus on available resources, obstacles and limitations. To remain person focused while recognizing the larger context can be challenging and as such, you will need to have a clear understanding of Person Centered Planning.

Objectives

Participants will be able to:

- Recognize that Person Centered Planning is an ongoing, dynamic process.
- Describe the steps involved in the process of Person Centered Planning.
- Demonstrate an understanding of the differences between traditional planning and Person Centered Planning, and the benefits of using person centered planning vs. traditional planning.
- Apply the principles of Person Centered Planning to the Individual Service Plan (ISP) development process.
- Generate strategies for involving the individual in their ISP Meeting.
- Develop goals and objectives based upon the guidelines presented in this module.
- Write goals and objectives that are person-first, positive, understandable and measureable.
- Exhibit an understanding of ISP and Person Centered Planning techniques when presented with QIDP application scenarios.

PERSON CENTERED PLANNING

"Person Centered Planning begins when people decide to listen carefully and in ways that can strengthen the voice of people who have been or are at risk of being silenced."

- John O'Brien

A Brief History

Prior to 1971, the only residential option for people with intellectual and/or developmental disabilities were large institutions. Basic care was available and services were provided based upon medical need. Doctors and nurses were the decision makers without consideration of individual or family desires.

In 1971, Intermediate Care Facilities for the Mentally Retarded (ICFs/MR) were established. Regulations were developed to improve services and the QIDP position was created. Focus of care continued to be largely based upon recommendation of experts such as doctors and psychologists and need for active treatment added.

In the 1980s, self-determination became a significant tenet of service. Self-determination is the belief that people with disabilities should have control over their own lives with day-to-day activities being based upon their choice and life goals. Residential options were opened within the community and large institutions were downsized. Service planning focused on the appropriateness of individual participation in a range of residential and day program options. An Interdisciplinary Team (IDT) which consisted of professionals and program employees developed goals and objectives for the person served. The goals and objectives reflected the services available within the programs, rather than a person's interests or life goals.

Person Centered Planning refers to a collection of approaches to planning that places the person served at the center of the process. An individual's team might consist of friends, relatives, neighbors, and even local business representatives all of whom commit to assist the individual in developing and achieving his or her personal goals based upon likes, dislikes, dreams and desires.

How Does Person Centered Planning Differ from Traditional Planning?

The Person Centered Planning process requires a shift in traditional thinking, actions, and ways of doing business to a process in which the individual directs the services and supports. The individual is the central driving force in determining his or her future vision, goals, hopes, dreams, supports and services.

The Person Centered Planning process requires family members, friends, and professionals to:

- Listen to the individual
- Attend to the details
- Be open and sensitive to situations that can be difficult and confusing
- Encourage and contribute to the dreams and desires of the individual
- Identify and support what really matters to the person
- Be willing to agree to disagree

The traditional planning process relied upon experts to develop programs and treatments to help people with disabilities overcome their areas of “weakness.” The underlying assumption was that the knowledge of experts better equipped them to make decisions for people with disabilities.

People who value individual differences, who advocate for person centeredness, believe that all people have the right to set individual goals that bring meaning to their lives. Agencies that support person centered planning find themselves continually being challenged to focus on the person rather than the system of available opportunities. This too will be your challenge.

The monograph, *Person Centered Planning* written by Mary Mercer offers ten questions that an agency can ask itself to better gauge their person centeredness.

1. Does the agency focus on deficits and weaknesses or on strengths and preferences?
2. Do the plans promote opportunities to build relationships and help people to be a part of their communities?
3. Do professionals have control over the person’s life direction?
4. Is the purpose of the meeting to shape services to each person’s vision?
5. Do plans for different people all look the same?
6. Do people at the meeting make decisions for the person?
7. Are people expected to fit into the daily, weekly and monthly schedules set by the agency?
8. Do teams dismiss individuals’ goals as unrealistic?
9. Are plans merely meeting regulations?
10. Do service providers assess the quality of plans based upon the dreams and goals of the person with whom the plan has been created?

The Differences between Person Centered and Traditional Planning

Using what you know to be true regarding the differences between traditional planning and Person Centered Planning, fill in the chart below.

Traditional Planning	Person Centered Planning
Doctors, psychologists, Nurses, Occupational Therapists are present at the meeting.	
	Focuses on the person's skills and uses their likes, interests as the basis of the plan.
Looks at the person in need of services as someone who has to get 'ready' for community life.	
The plan is designed to fit the person into a particular program, even if that program is not exactly what the person needs.	
	Meetings are scheduled to meet the time & place needs of the person served.
Goals and objectives are written around daily living, economic self-sufficiency and community integration.	

Person Centered Principles

The Five Accomplishments written by John O'Brien and Connie Lyle are frequently cited as the principles of person centered planning.

Community Presence: The sharing of the ordinary places that define community life.

- Person Centered Planning processes encourage the "building of community" around individuals. They help develop supports to facilitate relationships with people within the individual's community.
- Community as a place to visit, "an outing", is rejected.

Choice: The experience of autonomy both in small everyday matters (e.g., what to eat or what to wear) and in large, life-defining matters (e.g., with whom to live or what sort of work to do).

- All individuals have the opportunity to make informed choices and need to exercise control of their lives. Sometimes, in order to do this effectively, they must be supported by others and have a variety of experiences, either in their natural environment or from within the system.
- Resources to support the person are based on identified needs that the individual may have and are available in the community and/or in an agency.
- Natural supports presently available in the community are used first, then the agency resources. In instances where generic resources may not exist, they may need to be developed within the community.
- The idea that the opinion of a "collective" group of professionals is likely to be superior than that of the person is rejected.

Competence: The opportunity to perform functional and meaningful activities with whatever level or type of assistance is required.

- Person Centered Planning process builds on an individual's strengths, gifts, skills, talents, and contributions.
- Person centered planning rejects the notion that every person with intellectual/developmental disabilities must learn daily living skills at the "100%" level.

Respect: A valued place among a network of people and valued roles in community life.

- A person's cultural background is acknowledged and valued in the planning and decision-making process.
- Person Centered Planning requires that it is the individual who defines what is meaningful in his/her life and what really matters most to him/her.

Relationships: The experience of being part of a growing network of personal relationships that include close friends.

- Existing relationships are strengthened and new relationships are supported.

- New relationships are built and supported.

Person Centered Planning is a dynamic, rather than a static process. The key to Person Centered Planning is a commitment to continued support for a person to better understand themselves and their world so that they may live in a self-directed way. The process begins with the person at the center and grows outward. The individualized support plan is written in an effort to capture the desires and dreams of the person served and to detail the level and types of supports necessary for those to be achieved. It is revised as new opportunities or circumstances arise and when significant changes occur in the individual's life.
It is important to remember that a person centered plan is a means ***not*** an end. Flourishing and well-being is a result of continuous and intentional effort. The finest of all service plans does nothing if not implemented.

The commitment to Person Centered Planning can be challenging for many reasons. Consider the factors below and discuss how they may help or hinder the Person Centered Planning process.

- The size of the agency
- The size of a community residence
- Status of healthcare systems
- Parents who are guardians
- Guardianship through OSG
- Funding
- Access to transportation
- Safety
- Location of community residence
- Availability of employment options
- State and Federal Regulations

Getting to Know the Person

Too often service plans have a description of the person served that revolves around height, weight, health concerns, diagnoses, guardianship, etc., yet when we are asked to talk about ourselves these descriptors do not come up. While there are times when the information may be relevant to our understanding, the knowledge of the person must run much deeper.

Ask yourself how you might get to know a co-worker or a neighbor. You cannot come to know a person without spending time with them and the way you spend that time with them matters. QIDPs have many people on their caseload. Unless you commit to spending time with the people you serve, you will find it difficult to support them in obtaining their goals because you will not have an accurate understanding of who they are, what they want, what their strengths are and how to build upon those strengths.

Getting to Know You

Break into groups of three.

Person 3 will get to know Person 1 using the talking points below.

Person 2 will use the space below to take notes.

- Height
- Weight
- BMI (Body Mass Index)
- Marital status
- IQ
- Medical issues
- Medications
- Prior surgeries
- Biggest failure

After 5 minutes, ask a few of the people assigned as Person 3 to share what they learned.

Getting to Know You

Person 1 will get to know Person 2. Person 3 will use the space below to take notes.

Stay in the same groups and switch roles.

After 5 minutes, ask people to report the difference between the two conversations.

Which did they prefer? Were they comfortable asking/answering those questions?

Below is a narrative written by a QIDP to assist others with understanding and supporting a person served.

Getting to Know Greg: The Beginning of Person Centered Planning

Greg loves being around horses and wants the opportunity to do this every week. He gets up early every morning and tries to live what he refers to as the “cowboy life.” He wants to be connected to the horse culture. He likes to watch Bonanza reruns. He works part time at a stable on Wednesday, Thursday and Friday afternoons grooming horses and straightening up the stable. At this time he is looking for a full time job around horses or another part time job to increase both his income and time with horses.

He is learning to surf the internet to further explore his interests. He is looking for affordable housing in the country. He wants to create a budget so he can get his own place and have money to take girls on dates. He listens to country music and likes to attend country western dances. He is looking for a new pair of cowboy boots. He enjoys being outside as much as possible. He likes to attend the State Fair and enjoys watching the competitions especially if they involve horses. He likes to attend the dances there too.

Greg is beginning to volunteer with 4H and is looking to expand his role with this organization. He attends meetings once a month on the 2nd Saturday and will assist with the county fair this year. Greg attends St. Theresa’s Catholic Church on holidays with his family. He spends all holidays with his parents and talks to them on the phone at least weekly. He enjoys time with his father at their ranch, even though his father had to sell the horses a few years back. He is also close to his cousins Justin and Jessica, whom he likes to call occasionally. He also likes to email Justin. Greg also is improving his shopping and cooking skills to support his gluten free diet. Greg wants some time each week when he can be alone and would like opportunities to try out new activities in the community without his roommates along.

Discuss the following:

How likely is it that the writer of this narrative learned the information about Greg through one and only one conversation?
Does this narrative make you want to know more about Greg?
What are Greg’s goals?
What types of supports might you arrange to help Greg accomplish his goals?
What other questions would you ask Greg?

Discuss your Agency’s expectations and practices for QIDPs to get to know the people they support. Does your agency include a personal narrative within the service plan?

If your agency does not have an assessment tool to assist you with developing a personal narrative, or one to aid in Person Centered Planning, the following questions are examples. Wording should be changed to reflect a person's receptive language level.

<u>Questions you might ask…</u>

To better understand values:

- Do you have a religious affiliation?
- Do you attend or would you like to attend services on a regular basis?
- How does your spirituality impact your life?
- What is most important to you in life?
- How would you describe yourself?
- What kind of person are you?
- Who/What do you value?
- Do you have any traditions?
- Tell me about your family.
- What brings you happiness?
- Is there anything that makes you sad, frustrated, or angry?

To better understand preferences:

- Is there anything you can't live without?
- What do you feel very strongly about?
- What do you like?
- What are your interests and hobbies?
- Where do you prefer to spend your time?
- How do you like to spend the day?
- Tell me about your daily routine.
- Is there anything you dislike?
- What makes you smile?
- What things create comfort for you?

To better understand current level of independence and their satisfaction with current circumstances:

- Do you feel as if you have the opportunity to make choices on a daily basis?
- Are your choices listened to and supported?
- Do you receive encouragement to make choices and decisions?
- What supports are available to you?
- Do you feel you receive the supports that you need to live a successful life?
- Are you satisfied with your lifestyle and daily routine?
- What would you like to do more independently?
- What level of supervision do you feel you need for routine tasks?
- What makes you feel safe from harm?

- What are your talents?
- Tell me about the things you are good at.
- What are you proud of?
- Are there any conditions that threaten your health?
- What do you do to promote good health?
- Do you have any physical limitations or medical conditions?
- Do you feel comfortable discussing your choices and decisions with those around you?
- Is there any special assistance you feel that you need?
- What do you feel prevents you from being more independent?

To better understand hopes, wants, and desires:

- Do you have opportunities to learn new experiences?
- What skills would you like to learn?
- What educational goals do you have?
- What have you accomplished in life?
- Is there anything you'd like to try?
- What do you want your future to look like?
- What would you like to do more of?
- What would you like to do less?
- Would you like to work?

To better understand community participation:

- Do you feel you are a valued member of your community?
- Do you belong to any clubs or organizations?
- What are some things that you enjoying participating in with your community?
- Do you volunteer?
- What help do you need to participate in community life?
- Do you feel as if you have valued roles at work and in the community?
- What do you do during the day, the evening, on weekends?
- Where is your favorite place to go?

The ISP

The Individual Service Plan documents the individual's goals as well as the services and supports required to achieve those goals. It is one document but may take many forms. It is the result of a collaborative process, with the person served being the leader of that process. It is not the end of Person Centered Planning. Person Centered Planning is a dynamic process. The ISP may be altered to reflect life changes such as health, support needs and personal desires. The QIDP is responsible for facilitating necessary meetings to make those changes.

Functions of the Individual Service Plan

It is a tool that provides direction and guidance to support staff.

- Tells the reader about who the person is, what he/she wants, and who is helping the person
- Synthesizes pertinent information from assessments
- Identifies expectations for service and support
- Benchmarks skills, strengths and progress

It is a tool that reflects an agency's compliance with regulatory standards. The information below reflects the ISP requirements for Rule 115 Standards and Licensure requirements for CILA.

- Completed within 30 days of admission
- Be reviewed annually
- Include measurable objectives
- Objectives must have target dates of completion
- Include a goal for daily living
- Include a goal for economic self-sufficiency
- Include a goal for community integration
- Goals must be based upon assessments
- Must reflect person's needs and desires/preferences
- Contain signature of individual or guardian
- Identify all persons (staff and otherwise) who contributed to the development of the plan including relationship to the individual, title and agency affiliation, if applicable
- Include names of all service providers
- Include names of person responsible for facilitating goals and objectives
- Must have corresponding monthly progress notes
- Signed by QIDP
- Reflect progress or regress on specified goals and objectives
- Reflect amount of supervision

You may choose to discuss other relevant regulations regarding ISPs here.

Parts of the Service Plan

Service plan formats vary widely but most contain the following information:

Personal Narrative -This section summarizes some or all of what was learned during the planning process and tells the reader about the person and his/her current needs and wants.

Medical/Dental/Nutritional- This section contains a summary of significant medical issues. This includes any medication the person takes and the reasons. There may be nutritional information mentioned here, as well.

Background/Historical- This is a summary of significant events that have happened in the individual's life. These events may be a clue as to what shaped who the person is today.

Social Relationships- Here is where details of the person's social life are outlined. Important people are mentioned, as well as, all types of relationships (e.g., family, friends, work, staff members). Sometimes we draw maps to show how these people are related. These show the connections between people graphically.

Goals/Objectives- This section identifies the areas targeted for learning. The information for this section is gathered through interviews, assessments, and on-going interactions with the person. Both short and long term goals are found here.

Interests and Activities- Discusses interests of the person outside of work and home responsibilities. Leisure activities, hobbies, sports, or just about any other interest can be listed in this section.

Personal Values- This section makes a statement about what is important to the person. This is useful to know because often we are motivated by what we value the most.

Risks/Safeguards – This section indicates potential concerns around risk to the individual and identifies safeguards that are needed to mitigate these risks.

Sources of Comfort and Discomfort- This section will outline what things provide comfort, as well as discomfort to the person. Further, as people grow and change, this area of the plan may have to undergo change. Again, you will learn much about the person as you interact with him/her.

Assessments- The results of assessments or tests may be included here; for example, medical, PT/OT, speech and language, etc.

Strengths and Needs- Discusses strengths to build upon as well as areas requiring support.

Vocation- This section will describe the kinds of work the individual likes to do or would like to do.

Education- A summary of the person's educational background as well educational goals.

Financial - This area discusses financial information about the person including sources of income and needs for the future.

Communication Style- The best way to communicate with the person would be spelled out here. People can and do communicate in a variety of ways and it is important for you to understand how to communicate with each person you will be working with.

Learning Style- How the person learns is outlined. This includes strategies you can use to work most effectively given the person's specific situation.

Personal Rights- Provides information about personal rights that are most important to the person. Also, what, if any, rights restrictions might be in place and details of the situation.

Recent Life Changes- Anything that has recently occurred in a person's life which may have an effect on his/her day-to-day functioning should be noted here. This is another area that would be updated continually.

Vision for the Future- Just as you have dreams and hopes for the future, so do people we support in our programs.

You may choose to discuss your agency’s specific format here.

Individual Service Plan Meeting

It can be helpful to divide the tasks associated with the individual service plan meeting into three categories.

- Tasks that should be completed prior to the meeting, including assessments, meetings with the person and their significant others and planning the details of the meeting.
- Facilitating the meeting: The manner in which you facilitate the meeting will determine the quality of the experience for the individual.
- The QIDP is responsible for writing the ISP as well as coordinating implementation of the service plan.

Prior to the Meeting:

Assessments

Assessments are completed for a number of reasons including, evaluation of progress, understanding of regress, establishing strengths and/or limitations and regulatory requirements. Initial assessments are completed as part of the effort to better understand a person's needs and desires. Follow up assessments may be the result of identified need, best practices or regulatory requirement.

It is important to know and understand that the results of any one assessment are best understood in the context of other assessments. A psychological assessment alone will not provide you with a firm understanding of a person's level of functioning. A key role for the QIDP is to review and synthesize information across assessments in a manner that assists the person and their support team with creating a Person Centered Plan.

Through the selection of the assessment instruments and the interpretation of results, all assessments shall be sensitive to the individual's:

- Racial, ethnic and cultural background
- Chronological and developmental age
- Visual and auditory impairments
- Language preferences
- Degree of disability

Initial assessment for individuals with a developmental disability should include:

- **A physical and dental examination**, both within the past 12 months, including a medical history.

- Previous and current medication and the **level of ability to self-administer medications** or participate in a self-administration of medication training program.

- A **psycho-social assessment** including legal status, personal and family history, a history of mental disability and related services, evaluation of possible substance abuse, history of trauma and resource availability such as income entitlements, health care benefits, subsidized housing and social services.

- An assessment with **form IL 462-1215, “Specific Level of Functioning Assessments and Physical Health Inventory,” (SLOF)** for individuals with mental illness.

- **Inventory for Client and Agency Planning (ICAP)** (Riverside Publishing Co., 425 Spring Lake Drive, Itasca, Illinois 60143 (1986) or the Scales of Independent Behavior-Revised (SIB-R) (Riverside Publishing Co., 425 Spring Lake Drive, Itasca, Illinois 60143 (1996)) for individuals with a developmental disability.

- An **educational and/or vocational assessment** including level of education or specialized training, previous or current employment, and vocational skills, activities or interests.

- A **psychological and/or psychiatric assessment**; both must be conducted for individuals with both a mental illness and a developmental disability.

- A **communication screening** in vision, hearing, speech, language and sign language.

- **Others as required** by the individual’s disability such as physical therapy, occupational therapy and activity therapy.

Discuss your agency’s expectations with regard to the completion of assessments.

Assisting the Individual with Preparation

Meeting with the individual prior to the ISP meeting can and should be an important element of a meaningful and effective service planning. Both the QIDP and the person served benefit from taking time to prepare for the meeting.

Pre-meetings can help to:
- Ease nervousness
- Decide who should be invited
- Decide upon the time, location and structure of the meeting
- Develop an agenda for the meeting
- Review successes since the last meeting
- Decide upon priorities
- Set expectations
- Discuss and explain more complicated topics
- Prevent surprises

WHAT needs to be pursued and accomplished? This is the time to set priorities.

- What are the person's desired outcomes?
- What safeguards are needed? (safety issues/ health issues?)
- What clinical assessments are needed, if any?
- What community inclusions strategies should be in place?
- What obstacles need to be overcome?

WHO will help the person accomplish these goals?

- What networks or services are already in place?
- Consider new opportunities and ideas discovered during planning.
- Consider replacing existing supports and services that may not work for the person anymore.

Participants

Having the right people involved in the planning process is key. The size of the group should be comfortable for the individual. At times, the facilitator may need to keep the number of participants to a minimal level. In this situation, input from outside the planning meeting could be sought; a series of meetings could be scheduled; or small group pre-meetings may be held.

At a minimum, the ISP meeting must include:

- The individual receiving services (and guardian, if applicable)
- The QIDP
- The Independent Service Coordination (ISC) representative

In addition, the ISP meeting may include:

- People who know the person best (caregivers, friends)
- Other family members
- Other people providing supports and services (nurse, social worker, psychologist, nutritionist, occupational therapist, etc.)
- Friends
- Employers
- Church/synagogue members

HOW will it be accomplished? What action steps are needed?

- Consider how outcomes and other additional assistance will be pursued
- Acknowledge any barriers or obstacles
- What additional assistance does the person need help with? (for example, pain management, transportation, etc.)

WHEN will it be accomplished? This is a timeframe for a specific action. Do not confuse this timeframe with the duration of the Service Plan (which is usually ongoing).
For example, will it be accomplished in the next 6 months? Next month? Be sure to use a specific date.

Ask the person and family/advocate to prioritize what needs to be pursued or accomplished. Priorities could be sorted into high, medium, and low priority categories. Then, ask for the group's input. Record the priorities and the discussion.

Location, Date and Time

ISP meetings should be scheduled with consideration to a number of factors:

- The meeting date and time should be set so the person, family, and other key members can attend.
- The meeting place should be accessible and comfortable for the individual and his/her family so people feel free to speak. Consider any special accommodations that may be needed.
- Meeting schedules should be set far enough in advance to give members ample time to make necessary plans and to prepare for the meeting.

Facilitating the Meeting

As a professional providing service, the QIDP not only facilitates the meeting, but also advocates for the person. Balancing these roles is a complex task and the QIDP should be prepared for the contribution he/she will make by:

- Completing or Requesting new or updated clinical evaluations as needed (social work, psychosocial, nursing, psychological, physical, speech, hearing, speech, hearing, occupational therapy, physical therapy, psychiatric, neurological, recreational, educational, and other types of assessments and evaluations)
- Reviewing the previous ISP for possible changes
- Reviewing the progress notes for significant changes or discoveries since the last meeting
- Searching for new information that will impact discussions and decisions at the meeting
- Making arrangements for any special accommodations, such as interpreters

Be sure to have all the tools you will need to conduct the meeting, which may include such things as:

- Necessary reports and other written information
- Copies of last ISP with attachments
- Comfortable chairs in an arrangement that encourages participation by all

To set the stage for a comfortable and successful meeting:

- Provide coffee/juice/water/snack
- Suggest that the person served sit by the person that they are most comfortable with
- Provide an agenda
- Introduce everyone and allow for a bit of conversation prior to starting

Although each meeting has a different purpose and agenda, they all have the same basic structure. Each has a beginning, middle, and end. At the beginning, you set the tone and direction; you create roles and ground rules to guide participant behavior. In the middle, you discuss the agenda and at the end, you confirm agreement regarding necessary actions. Recognizing your role as both leader and facilitator will assist in maximizing the productivity and experience of the meeting for everyone.

Much of the 'skill' in facilitating comes from the facilitator's knowledge, approach, personality, experience, beliefs, values, attitudes, skills, habits and personal expectations. Good facilitators are always learning and looking to improve certain qualities and characteristics within themselves.

During the meeting consider the following:

- Open ended questions will create more dialogue than simple yes/no questions
- Encourage the participant to contribute as much as they can
- Allow for time for the participant to gather thoughts
- Guide discussion to stay on topic

Strategies for Involving People in their Meetings

There are times, despite the best intentions of keeping the meeting focused on the person, when the person seems to feel like a bystander. This feeling may also be shared by the person's family or advocate when service providers talk in technical terms or global issues. The person may have cognitive limitations or learning disabilities that affect their receptive or expressive language abilities. Regardless of the person's abilities, there are some general strategies for involving people in their meetings.

- Look at the person frequently
- Address the person by name
- Ask the person questions
- Refocus questions inappropriately directed towards others
- Do not allow the group to hold third person conversations about the individual (as if the individual is not there)
- Consider a break if needed

The person who is the focus of planning and is physically unable to speak presents a unique challenge. Because the person is unable to verbally participate in the ISP meeting, it is important for the group to take the time and energy to understand the true desires and preferences of the person.

Find a way the person could possibly communicate (e.g. through some varied type of yes/no response mode, a system for pointing or looking at pictures or representations of preferred activities or choices). Allocate time for sharing experiences with the person to gain some perspective on the subtleties of how this person communicates his or her likes and dislikes, pleasures and pains, and other forms of preference-related concepts. Use strategies for seeking the input of close friends and family members who have known the person for a long time and who already possess some firsthand knowledge of the person's preferences and desires.

Creative ISP Meetings

Break into small groups. Discuss creative alternatives to the traditional service plan meeting scenarios in the left column.

Traditional Meeting	Creative Alternative
Location: Agency conference room	
QIDP sits at the "head" of the table	
QIDP starts the meeting and introduces everyone	
Discussion focuses on assessment results	

Writing Goals and Objectives

“The height of an intellectually disabled person’s level of functioning is determined by the availability of training technology and the amount of resources society is willing to allocate and not by significant limitations in biological potential.” -Marc Gold, The Principles and Practices of Universal Enhancement, Tom Pomeranz.

Discuss the implications of the statement above.

Planning for the future involves setting valued outcomes/goals. The goal is based on the person’s needs, and should be written without regard to the availability of services. The goal statement is an expectation of what the person will accomplish. Goals are written in a positive manner.

The following questions are helpful when discussing potential goals:

1. How will this person’s life be better as a result of this goal?
2. Is it something the person and/or guardian wants?
3. Will it increase the number of places and people in the person’s life?
4. How does this goal add meaning to this person’s life?
5. It is chronologically age appropriate? (young adult, middle age, retirement)
6. It is functional for the person’s quality of life and will there be opportunities to practice?
7. Will it enhance the person’s physical condition?
8. Will it result in increased skill?
9. Will it yield status enhancement?
10. Acquisition Probability: Do the long range benefits of this goal warrant the time investment now?

Learning Objectives

Learning Objectives are defined as behavior/skill acquisition or change on the part of the person for whom the plan is written. Learning Objectives were previously referred to as “behavioral,” “teaching,” or “training” objectives that assist the person in achieving their overall goals. A learning objective is an attempt to clearly define the criteria for successful completion of a skill. Objectives are measurable intermediate steps between the person’s present level of performance and the desired level as stated in the goal.

Well written Behavioral Objectives are:

- Sequential
- Relate directly to a goal
- For skill acquisition
- Measurable
- Singularly stated

When writing a behavioral objective it should be composed of the following five elements.

- Conditions
- Person
- Behavior
- Performance Criteria
- Timeline

Conditions – Describes the things that have happened or are required to happen or circumstances required to carry out the program. Example: “When checking out at the grocery store . . .”

Person – Use the individual’s name, not nickname, not “he” “she” or “you”

Behavior- Specify <u>one</u> behavior in measurable and observable terms. The behavior should be overt (sensed through one of the senses and able to be measured), not covert. Look at some differences between these terms:

COVERT	**OVERT**
Distinguish	Draw
Conclude	Fill in
Concentrate	Underline
Think	Repeat out loud
Recognize	Point to
Be aware	Walk
Infer	Count out loud

Performance Criterion – Describes the degree to which the person will complete the task satisfactorily. It is important to note here that nobody holds themselves to the standard of perfect 100% of the time. The key here is to choose objectives that uniquely fit the person’s desires and to measure them using criteria that are both appropriate to the person and to the task.

- How many—i.e., the number of responses; ex.: “will cook spaghetti for her family 2 times”
- How often--# of responses that are time-related; ex.: “will awaken to his alarm Monday through Friday.”
- How well—to what degree or at what level of accuracy; ex. “will record the name, telephone number, and time when taking telephone messages...”

Timeline - The timeline is the date by which the performance criteria should be achieved. The timeline date must always include month, date and year.

Consider the following objective:
John will walk from his apartment to work without assistance in less than 15 minutes, without breaking any safety rules, for 10 consecutive working mornings.

Discuss the following:

What is the observable behavior?
How well will John need to complete the behavior?
How many times will John have to successfully complete the behavior?
Are there any particular conditions or given circumstances required and if so what are they?
How will it be measured and/or recorded? By whom?

Writing Learning Objectives

Use the 5 elements of behavioral objectives to create strong, one sentence objectives for each of the following behaviors.

Behavior	Learning Objective
John cleans.	
Sophie brushes her teeth.	
Greg does laundry.	
Cynthia knows her meds.	
Richard goes to the library.	
Aubrey pays the cashier.	
Doug makes his bed.	
Gina makes dinner.	
Eddie goes grocery shopping.	

Plan Implementation

At least monthly…

The QIDP must review the services plan and document that:

- Services are being implemented as identified in the service plan.
- The person is or is not making progress.
- Services continue to meet the individual's needs or need modification.
- Actions are recommended and implemented when needed.

Annual Reassessments

Annual reassessments for individuals with an intellectual/developmental disability include:

- A physical and dental examination including a review of medications.
- The Specific Level of Functioning (SLOF) for individuals with a mental illness or Inventory for Client and Agency Planning (ICAP) or Scales of Independent Behavior (SIB) for individuals with a developmental disability.
- An annual psychiatric examination for individuals with a mental illness.
- A risk assessment that evaluates potential risks to the health, safety and welfare of the person served as well as relevant strategies/safeguards to mitigate those risks.

Need for modifications to ISP

Recognizing that life circumstances change there will be occasions when the individual service plan no longer captures the needs of the person. When this occurs revision to the plan can be made. Revisions can only be made to a service plan through a team meeting. Changes may be made by attaching an addendum to the ISP. Addendums are filed with the current ISP and distributed to all appropriate parties.

The addendum must:

- Be dated
- Be approved in writing by the participant or guardian, if appointed
- Be approved in writing by the responsible waiver QIDP
- Be approved, in writing, by the participant's Independent Service Coordination (ISC) representative

Learning and Teaching

For many years the classic learning theory concepts and techniques of successive approximations, chaining and backward chaining have been the cornerstone of teaching people with intellectual and developmental disabilities. In recent years, total task teaching has gained professional preference. The primary difference is that in chaining the learner is only assisted with the "step" of the task they are learning and with total task the learner is assisted through the entire task. The clear advantage of total task is that all parts of the task are completed, "rehearsed", each time the task is completed.

Learning Modalities are the sensory channels or pathways through which individuals give, receive, and store information. Everyone has a mix of learning styles. Some might find they have a dominate style of learning, while others use different styles in different circumstances. People with autism learn and communicate best using visuals. Teaching new skills to individuals with developmental disabilities takes time, patience, and persistence. The key is to recognize and understand what techniques best suit individuals served to ensure quality of learning. The same applies when teaching support staff. Understanding that people learn through different senses can help you set the stage for engagement and learning by creating supports that maximize interest and curiosity.

Consider the Following Information about Learning Styles

- Visual learners learn best by seeing and watching
    - Looking at pictures
    - Watching videos
    - Reading
    - Using flashcards
    - Writing on the board
    - Looking at charts or diagrams
- Auditory learners learn best by listening, hearing, and speaking
    - Listening to lecture
    - Joining discussion groups
    - Reading out loud
    - Repeating what they are learning
    - Asking a lot of questions
        - Getting verbal reinforcement
- Tactile/kinesthetic learners learn best by moving, experiencing, doing, and touching.
    - Drawing
    - Building or creating
    - Touching materials
    - Doing physical activities
    - Role-playing
    - Going on field trips

Recommended Reading & Resources

Although we will try to cover a great deal of material with you today in class, the topic of Person Centered Planning is a broad one that requires continued study and attention throughout your career. We recommend the following resources as good places to start with regard to furthering your knowledge and understanding of this important topic.

- A Little Book About Person Centered Planning, Volume I by *John O'Brien and Connie Lyle O'Brien*

- Implementing Person Centered Planning: Voices of Experience, Volume II by *John O'Brien and Connie Lyle O'Brien*

- Innovating for People: Human-Centered Design Planning Cards by LUMA Institute

- Person Centered Planning by Don Kincaid (As found in Positive Behavioral Support: Including People with Difficult Behaviors in the Community by *Dunlap, L.K. Koegel, and R.L. Koegel*

- Person Centered Planning: Helping People with Disabilities Achieve Person Outcomes by *Mary Mercer*

- The Principles and Practices of Universal Enhancement, 4-Volume Set by *Thomas E. Pomeranz, Ed.D.*

- Service and Support Agreements: The Foundation for Futures Planning by *Art Dykstra*

- Person Centered Planning Education Site, *Cornell University*
  http://www.personcenteredplanning.org/index.cfm

QIDP Professional TRAINING

Illinois Department of Human Services

Module 1: Introduction to the World of the QIDP

Module 2: Leadership and Communication

Module 3: Behavioral Supports

Module 4: Person Centered Planning

Module 5: Record Keeping

Module 6: Advocacy, Rights, and Resources

Module 7: Environmental and Safety Supports

Module 8: Medical Supports

Module 9: Rules and Regulations

Module Overview

Module 5 Introduction

Why is documentation important to you, as a QIDP?

QIDPs are typically responsible for maintaining the individual record. As a QIDP, you will document services provided to each person probably more than any other professional at your agency. Additionally, QIDPs frequently hold the responsibility for collecting documentation from other professionals such as physicians, psychiatrists, etc. and ensuring that those records are kept within the record according to agency policy.

Objectives

Participants will be able to:

- Apply principles of documentation to the responsibilities of a QIDP.
- Identify the importance of record keeping and documentation in the human services field.
- Recognize the importance of effective record keeping strategies and confidentiality agreements as they pertain to a QIDP and the staff he/she is responsible for.
- Demonstrate an understanding of accurate documentation.
- Describe and explain the significance of the documents that may be found in an individual's file.
- Demonstrate an understanding of record retention principles, regulations, and requirements.

DOCUMENTATION

"Accuracy of statement is one of the first elements of truth; inaccuracy is a near kin to falsehood."

-Tyron Edwards

Why is documentation important?

- **Records provide a history:**
    - Records of previous services and supports may assist with the development of current services and supports.
    - Historical health, educational and service records are sometimes needed for future health, educational and service needs.
    - Maximizing a person's health is much easier to do when you have knowledge of prior health needs and familial patterns of health.
- **Records assist with continuity of services and supports:**
    - Although service planning is reviewed annually, learning occurs over time. Skills, learning and personal interests do not naturally start and stop every twelve months but rather ebb and flow over time.
    - Infrequent concerns may be overlooked if not documented. Patterns and trends can be more easily identified over time.
- **Records help us comply with rules and regulations:**
    - Funding and governing bodies have specific requirements regarding record keeping. Most agencies are reviewed by such bodies annually. Failure to meet record keeping standards may jeopardize an agency's funding and capacity to provide services.
- **Records can help us evaluate organizational outcomes:**
    - Records and analysis of the information in those records can assist an agency with evaluating its performance across time. Maintaining and increasing quality of service relies upon an agency's understanding of many factors and details that can only be known through documenting and recording.
    - Records provide accountability.

Confidentiality

With the enactment of the Health Insurance Portability and Accountability Act (HIPAA) staff must be diligent in assuring that their practices remain in accordance with state HIPAA regulations. The intent of this statute is to assure that an individual's personal information is not shared without permission. A central aspect of the Privacy Rule is "minimum necessary" use and disclosure. A covered agency or person must make reasonable efforts to request, use, and disclose only the minimum amount of protected information needed to accomplish the intended purpose of the request.

Confidentiality is an important component of a person’s plan. Conversations should be kept confined to the meeting room and care must be taken to assure topics are not discussed in hallways, parking lots, etc. Likewise, after the meeting, care must be taken that papers containing identifiable information are not left lying about.

When discussing an individual supported during a meeting, such as Human Rights Committee, some organizations use initials, identification numbers, etc. to keep complete anonymity even from the committee members. It is agreed that if discussion includes someone who is not receiving services at the agency, the person’s identity must be kept confidential.

When records are shared or requested, informed, written consent must be obtained. Consents should be written in plain language that is easy for the individual served to understand. The use of pictures may be necessary. According to the Mental Health and Developmental Disabilities Confidentiality Act, the consent should be in writing and contain the following elements.

- The person or agency to which disclosure is to be made.
- The purpose for which disclosure is to be made.
- The nature of the information to be disclosed.
- The right to inspect and copy the information to be disclosed.
- The consequences of a refusal to consent, if any.
- The calendar date on which the consent expires.
- The right to revoke the consent at any time.

Record Retention

As a general rule, records in individual files that contain HIPAA information should be retained 6 years after the record is closed (e.g., individual moves, death etc.). Records may be stored in inactive or closed files or in forms other than paper such as electronic or online, digital or analog media.

What is “PHI”?

It is Protected Health Information about a patient/consumer held by health care providers (includes CILAs) and health plans. Examples include:

- Patient’s medical record number
- Patient’s demographic information (e.g. address, telephone number)
- Information doctors, nurses, other health care providers put in a patient’s medical record
- Images of the person
- Conversations a doctor has about a patient’s care or treatment with nurses and others
- Information about a person in a doctor’s computer system or a health insurer’s computer system
- Billing information about a patient at a clinic

Thinking about it another way, PHI is any health information that can lead to the identity of an individual or the contents of the information can be used to make a reasonable assumption as to the identity of the individual.

For more information on record retention and privacy rules see:
http://www.hhs.gov/ocr/privacy/hipaa/understanding/summary/

Record Keeping Guidelines

- To make a correction, draw a single line through the error, initial, and then write the corrections. White out should not be used.
- If not typed, entries should be written neatly and legibly.
- When referring to people, proper names should be used.
- Documents should only be signed after checking accuracy.
- Blue or black ink should be used as colored ink is not considered professional.
- Care and consideration should be given to content. Content should be accurate, free of slang and unnecessary editorial comments.
- Information should be recorded chronologically.
- Be factual: Only document what you personally observed. Use quotes when possible.
- Be Precise: Specific objective language should be used. General terms should be avoided.
- When possible, measurable quantities should be used. Phrases such as “a lot” or “hardly ever” should be avoided.
- Unused space should be filled with a single line to indicate no further information.
- Signatures should be consistent with each signatory’s legal name and should indicate title.
- Signatures should be dated.

Insert agency specific information here.

Accurate Documentation?

Directions: Rewrite the subjective sentences using required record keeping guidelines.

Subjective Documentation	Objective Documentation
Bob seems to have a stomach ache.	
Courtney acted out.	
Sarah fell on the driveway.	
Joseph appears restless.	
Hillary would not eat.	
Steven should go to the doctor for a physical soon.	
Robert would not get out of bed.	
Jorge attacked Frank.	

Types of Records

The Individual/Clinical File/Case Record

While the format of the clinical file will differ from agency to agency, much of the content will be the same. Below are the eight most common inclusions.

Admission Information

This section includes such documents as the application, placement award letters, Medicaid waiver redeterminations, IDHS referral information, personal property list, IDPA notice of change, admission, transfer, and ISC reviews.

Medical Information

This section includes documents such as medical and psychiatric visits, physician orders, and a list of current medications. Annual physical, dental, vision, nutritional reports, and nursing notes, if available, should be filed in this section. Given the amount of documentation that this section sometimes has, it is sometimes filed in a separate record.

Clinical Referrals, Assessment, and Ancillary Service Reports

This section includes documents such as assessment reports or monthly updates from various therapies, diagnostic results, and current levels of functioning.

Current Programs

This section includes documents such as the ISP, individual's planning meeting documentation, caseload assignment sheet, monthly summaries, and visit reports.

Behavioral Information

Behavior plans, programs, and functional assessments are placed here.

Legal Documents and Consent Forms

Documents might include guardianship papers, birth certificate, information releases, restraining orders, medical treatment and authorization forms, and power of attorney papers.

Correspondence

Other types of correspondence should be included in this section of the records.

Vocational

Documents relating to an individual's work including any meetings, summaries of work shifts, and Job Coach information are placed here.

Insert agency specific information here.

QIDP Monthly Summary

In accordance with state and federal law, the QIDP must provide a monthly summary which describes progress on goals and objectives in the service plan, as well as information on the overall status of the person.

The monthly summary should address current program status including progress or lack thereof for each objective; and if no progress is being made, the reason must be indicated. This information should be specific enough so that it directly relates back to the overall outcome that the person desires.

Purpose of Monthly Summary

- Comply with federal and state law
- Communication of relevant information
- Reflect current status of progress and needs
- Reflect changes that have occurred since last summary

The Monthly Summary must include…

- Behavioral concerns
- Comments on whether the behavior plan is working
- Family activities and involvement including Family/Guardian contact, visits
- Health and medical information including doctor appointments, medication changes, general health changes, weight changes and health concerns
- Overnight visits
- Community involvement
- Overall program progress, concerns, or changes needed
- Comment on whether the current plan continues to meet the person's needs

Insert agency specific information here.

The Individual Service Plan

The individual service plan is often referred to as the ISP.

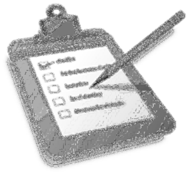
Purpose of ISP

- Ensure compliance with standards and rules established by various licensing, certifying, and accrediting bodies
- Utilized to establish reimbursement rates based upon the services and supports required by the individual
- Document the personal goals of the individual and the supports and services needed to accomplish those goals

- Record the results of assessments and reassessments
- Create a snapshot of the person’s progress made toward achieving goals and objectives
- Record the Community Support Team’s deliberations and decisions about the appropriateness of the plan, as well as recommended revisions and/or additions

The ISP must be…

- Data-based
- Goal-directed
- Monitored
- Reviewed annually by the individual’s support team



Insert agency specific information here.

Legal Documents

The QIDP is responsible for assuring that all legal documents are present and handled according to agency policy and procedure. The following documents are examples of what might be found in the file:

- Guardianship
- Birth Certificate
- Restraint Orders
- Do Not Resuscitate Order
- Releases of Information
- Receipt of Personal Property
- Individual’s Review of Human Rights
- Restriction of Rights
- Change in Legal Status
- Incident Reports
- Power of Attorney
- Information about funeral arrangements, burial/cremation, etc.
- Voter Registration
- Social Security Application

Consent and Authorization for:

- Treatment
- Special Behavior Programs
- Medications
- Emergency Treatment
- Living Will
- Advance Directives
- Release of Information
- Marriage/Divorce

Communication Log Books

Some agencies use a communication log book to highlight information for the next shift coming on duty. Significant events such as behavioral, environmental, and/or health issues can be highlighted here as a quick reference for staff to read at the beginning of their shift.

Daily Service Notes

The daily service note, sometimes called a progress note, is another means of sharing information about services and supports provided. Designated staff will usually complete the note on each shift. These progress notes are an important reference for the QIDPs monthly summary.

Daily Service notes are also used for:

- Staff to convey important information about the person for the next shift
- Keeping staff up to date with daily activities; day trips, medical visits, etc.

Incident and Event Reports

Documentation about particular types of incidents and events is required by Agency policy and or state governing/funding entities. These incidents include employee injury, injury of person served, serious illness, hospitalizations, accidents, unusual behaviors, severe maladaptive behavior, use of restrictive interventions, missing persons, bloodborne pathogen incidents and other similar events.

On occasion in addition to documentation it is necessary and required to contact the guardian and/or OIG, IDPH or other agency providing oversight. A timeline for completing documentation and reporting is associated with events of particular types.

Insert agency specific information here.

Documentation Guide

Directions: With the class, complete this documentation guide as it relates to your particular agency. The first example has been completed for you.

Issue	Example	Where to Document	Other Necessary Action
Work Related	*Difficulty with Job*	*Progress Note*	*No*
Elopement			
Vehicle Accident			
Yelling			
Physical Aggression			
General Upset			
Fall (No Injury)			
Burn (While Cooking)			
Unusual Crying			
Report of "Not Feeling Well"			
Seizure with Injury			
Blood Exposure			
Fall (Bruise on Leg)			
Alcohol or Drugs			
Sexually Inappropriate Behavior - Self			
Sexually Inappropriate Behavior - Others			
Parent Phone Call with Message for Staff			
Newly Scheduled Family Visit			

Documentation Orientation

Mario works as a DSP in a residence and helps support Tom who lives there. Yesterday, Mario noticed that Tom was acting differently from his 'usual self.' Below is the documentation that Mario wrote about Tom.

Can you find any errors in Mario's documentation?

8:15 Sunday, 1/8/14

Tom seems crabby and he's complaining a lot. He's complaining that his stomach aches. He didn't eat most of his dinner. He just wants to lay down and watch TV. I think he probably has heartburn because of what he said. I told him to just go to bed early and maybe he'll feel better tomorrow.

Can you make some suggestions to help Mario with his documentation? Write your suggestions below.

- ➢
- ➢
- ➢
- ➢
- ➢
- ➢

You might choose to review several agency specific documents to discuss and practice the information learned above. Possible documents to review: Seizure Reports, Accident Reports, Medical Visit Summary, etc.

Recommended Reading & Resources

Although we will try to cover a great deal of material with you today in class, the topic of record keeping is a broad one that requires continued study and attention throughout your career. We recommend the following resources as good places to start with regard to furthering your knowledge and understanding of this important process.

- Fundamentals of Case Management Practice: Skills for Human Services by *Nancy Summers*
- Individualized Service Plans: Empowering People with Disabilities by *Paul Spicer*
- Legal and Ethical Aspects of Health Information Management by *Dana McWay*
- Treatment Planning for Person-Centered Care: Shared Decision Making for Whole Health by *Neal Adams and Diane Grieder*

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Module Overview

Module 6 Introduction

Why are these things important to you, as a QIDP?

In your role as QIDP, you are charged with the responsibility of ensuring individuals receive the services they need and ensure the services are provided in a manner which conveys respect and keeps the person's interests and rights in the forefront. To that end, you advocate on their behalf and support them in advocating for themselves. You assure the ongoing integrity of their person-centered support plan, continued involvement of the individual's circle of support and foster the development of community relationships and opportunities for the individuals to have meaningful community lives.

Objectives

Participants will be able to:

- Explain the importance of advocacy in the field of human services.
- Describe the different types of advocacy and the general roles and responsibilities of an advocate.
- Exhibit a brief understanding of the significance of various litigation as it pertains to advocacy and rights.
- Demonstrate an understanding of the importance of equality and rights for individuals with intellectual and/or developmental disabilities.
- Determine who to contact in the event of guardianship or rights issues.
- Explain the selection process and qualifications for guardianship requests.
- Determine the presence of rights restrictions in given situations.
- Describe and explain various aspects of personal finances for individuals with intellectual and/or physical disabilities including the ABLE act, spend downs, trust funds, and SNAP/Link Cards.
- Assist in managing personal finances for individuals with intellectual and/or developmental disabilities.

ADVOCACY

"How wonderful it is that nobody need wait a single moment before starting to improve the world."

-Anne Frank

Advocacy is not about acting in what is perceived to be the person's best interest, but is about standing with a person to ensure they are able to have a say and get what they want and need. Advocacy is part of everyday life. At some point in our lives, most of us will have needed the support of someone we trust to help us speak up for ourselves.

Some people find that advocacy helps when they feel they are not being listened to, or are not getting what they need and would like some support. Anyone may need advocacy at some point in his or her life, but it becomes especially relevant in situations when:

- People are being treated unfairly as a result of other people's prejudices, or their own vulnerability, or both.
- People feel they have no family, friends or anyone in the wider community whom they can turn to for support.
- People may have professional paid workers involved in their lives who are not providing services which take into account their needs and/or requirements.

Advocacy is a relationship between the person, group or organization providing advocacy - the advocate, and the person who is being supported.

Different Types of Advocacy

There are many types of advocacy. There are clear links between the different types of advocacy and often advocacy of more than one type is used.

Citizen Advocacy

This type of advocacy is a one-to-one partnership between two people. The Citizen Advocate is a volunteer who usually forms a long-term relationship with their partner and takes a personal interest in ensuring that their partner's interests are effectively represented. The relationship is based on trust, commitment and loyalty. There is an element of emotional support and friendship as well as a social element, which may involve introducing the partner to new experiences and/or activities.

Independent (Issue-based) Advocacy

This is also called crisis or case advocacy. A one to one partnership between two people, often provided by paid advocates. Independent advocacy shares the same principles as Citizen

Advocacy, but is usually short-term, dealing with a specific issue in a person's life. The relationship is normally time limited, but may last for several months.

Self-Advocacy

Seen by many in the advocacy movement to be the most ideal form of advocacy, and one which all other types of advocacy should be aiming to work towards. Self-advocacy involves people speaking out for themselves, expressing their own needs and representing their own interests. Often people with some form of disability may have received some support in achieving self-advocacy – this is a model employed by People First. To learn more about People First, you can visit www.PeopleFirst.Org

Group Advocacy

Where people come together to represent shared interests or goals and works by offering mutual support, skill development and a common call for change with the intention of developing or changing services.

Peer Advocacy

Support from advocates who themselves have experience of using particular services such as mental health or disabilities services. It can involve people speaking up for those who cannot do so themselves and may link with group advocacy.

Legal Advocacy

This type of advocacy is representation by legally qualified advocates such as attorneys.

Professional Advocacy

Representation by members of services involved in a person's life, for example social workers or health workers. A QIDP can be viewed as a professional advocate.

Family and Friend advocacy

Where a person's family member or members or friend(s) play a part in advocating on their behalf. Most of us have used or provided this support at some point in our lives, whether we realized it or not.

The Role of an Advocate

An advocate should be available to:

- Support the person in expressing their views, concerns and opinions.
- Speak on behalf of the person, raising any issues where required, but only as the person wishes. It is desirable that people regain their own power to speak for themselves where possible. Advocates will support people when they speak for themselves.
- Develop a one-to-one relationship with a person for as long as the person wishes it to continue.
- Allow the partner to make his or her own decisions and choices whenever possible, even if the process of engagement is slow and uncertain. An advocate ensures that their person retains maximum control.

- Remain neutral and independent of organizations and services that the person is dealing with.
- Understand and respect the rights of the individual at all times.

Kara's Voice- A story of successful advocacy

Kara lived a fairly independent life because of an iPad and a 99-cent app called Aida. She has significant challenges with memory and time management due to a severe traumatic brain injury suffered as a child. Technology has helped her to have a self-determined life. Many people with disabilities found this particular app helpful in remembering appointments, meetings, or even daily life activities. Using this app allowed them to live independently. Unfortunately, the Aida app that guides Kara's life underwent revisions from iOS5 to iOS8. Because of the updates, voice prompts were no longer available and as a result, it lost much of its usefulness. Without the prompts, Kara has the ability to get lost in what she doing and breakfast could easily stretch for hours. A voice prompt lets Kara know that breakfast time is over and it is time to move on to the next thing.

Kara's mom, Alice, emailed and called Apple Inc. for 3 years to restore the voice functionality. She emailed and called Apple many times over several years trying to explain the life-changing aspects that were taken away. No one at Apple listened. In 2015, Kara's mother launched an online petition to get Apple's attention as to how these updates affected people's lives. Several newspapers picked up the story. A number of agencies that support people with intellectual and developmental disabilities also joined the social media cause.
Imagine the joy that Kara's mom felt the day that she received a call from an Apple Accessibility team member wanting to learn more about the benefits of the app and the challenges that the system updates had caused. She worked diligently to educate Apple Inc. In July 2015, Apple announced that the upcoming release of a new version which will contain updates so that the Aida Organizer app will once again allow for voice functions.

Rosa's Law

A journey that began as one Maryland family's battle for respect and acceptance for their daughter and sister, Rosa, became a significant milestone in the ongoing battle for dignity, inclusion and respect of all people with intellectual disabilities when United States President Barack Obama signed bill S.2781 into federal law on October 5, 2010.

A family in Edgewater, Maryland provided the inspiration for the law. Nina Marcellino is the mother of four children, including Rosa, a child with Down syndrome. In 2009, Marcellino learned that Rosa had been labeled retarded at school. Marcellino didn't allow the R-word in her house, and none of her children described their sister that way. Nina teamed up with other parents and her state delegate to introduce a bill to change the terminology in Maryland state law. Before the bill was brought up for consideration in the Maryland General Assembly, they held a hearing on the implications of changing the term.

There were several witnesses at that hearing, but the testimony that had the greatest impact was given by an 11-year-old boy: Rosa's brother, Nick. "What you call people is how you treat them," Nick said. "What you call my sister is how you will treat her. If you believe she's 'retarded,' it invites taunting, stigma. It invites bullying and it also invites the slammed doors of being treated with respect and dignity."

Known as "Rosa's Law," the law removes the terms "mental retardation" and "mentally retarded" from federal health, education and labor policy and replaces them with people first language "individual with an intellectual disability" and "intellectual disability."

In 2008, Special Olympics launched the website www.r-word.org to combat the inappropriate use of the R-word in common usage and helped lead protests against media use of the word in response to the film 'Tropic Thunder.' In 2009, the youth-led "Spread the Word to End the Word" campaign launched with rallies in K-12 schools and universities around the country, enlisting young people to combat use of the word and collecting more than 100,000 signatures to pledge inclusion and respect towards all people.

Champions of Rosa's law made sure by updating language in federal law that the bill would not expand nor diminish services, rights, responsibilities or educational opportunities duly owed to individuals with intellectual disabilities. It simply makes the federal law language consistent with that used by the Centers for Disease Control, the World Health Organization, and the White House through the President's Committee for People with Intellectual Disabilities. The changes will occur during routine revisions to laws and documents over the next several years. Since the alterations will be implemented gradually, the legislation is not expected to incur any cost.

Ligas Lawsuit Information (Illinois)

In a typical class action, a plaintiff sues a defendant or a number of defendants on behalf of a group, or class, of absent parties. This differs from a traditional lawsuit, where one party sues another party. Class actions are most common where the allegations involve a large number of people who have been injured by the same defendant in the same way. Instead of each injured person bringing their own lawsuit, the class action allows all the claims of all class members—whether they know they have been injured or not—to be resolved in a single proceeding. This type of action has been a common means of forced social and policy reform in the field of intellectual and developmental disabilities. Ligas v. Hamos is one such law suit.

The Ligas v. Hamos lawsuit was filed on July 28, 2005, on behalf of adults with developmental disabilities living in Illinois in private, State-funded Intermediate Care Facilities for Persons with Developmental Disabilities (ICFs/DD) who want to move to community-based services or settings and on behalf of adults with developmental disabilities living at home who want community-based services or settings. On June 15, 2011, the Ligas v. Hamos Consent Decree was approved by the Court.

Principles of Ligas

- People with disabilities will have a say and a choice about how and where services and supports will be provided.
- People who want services in the community will have that option.
- Person-centered planning will be used as the cornerstone in documenting individual needs and preferences.
- Services will not be limited to those which are currently available.

Timeline for Community Services for Class Members Living in ICFs/DD

- Within six years of the decree (6/15/17), all class members who live in ICFs/DD who request community services will transition to community settings.

Ligas Class Members

- A member must be 18 or older with intellectual or developmental disability and Medicaid eligible; and
- A member lives in a private ICF/DD with 9 or more residents or lives in the family home seeking services; and
- The State of Illinois has a "current record" of the person seeking Community-Based Services or placement in a Community-Based Setting

Equip for Equality

Equip for Equality (www.equipforequality.org) is an independent agency whose goal is to ensure that the civil and human rights of people with disabilities. This is accomplished through self-advocacy assistance, providing legal services, influencing public policy, monitoring, and training.

Equip for Equality also receives funding for special projects targeting specific needs, which might include assistive technology, voting rights, traumatic brain injury, etc.

Understanding Rights

Rights are Fundamental to all People

The Universal Declaration of Human Rights of the United Nations (see Resources) declares all human beings must be endowed with inherent dignity and “the equal and inalienable rights of all members of the human family” which are the basis for “freedom, justice and peace in the world.”

The most vulnerable members of any population often need advocates to defend them against disregard or contempt for their rights. Education of those who provide care and assistance for others needs to be on-going, with a goal of creating a culture that recognizes and treats adults as adults regardless of their disability.

The Council on Quality and Leadership provides the following suggestions for establishing a philosophy and culture where all people are seen as equal and all decisions are made with great thoughtfulness.

- Assure that all employees understand that the concept of “rights” goes far beyond the initial training and annual review that is required in most state systems. Rights are all encompassing and are not restricted to “service” or “treatment” rights.
- Incorporate the Universal Declaration of Human Rights of the United Nations and the U.S. Constitution in your training and assure that all staff members, people supported, and other interested parties understand these documents.
- Establish a culture in which adults are seen and treated as adults regardless of their disability.
- Host on-going conversations about rights and responsibilities with staff members and people supported to improve people’s understanding of these issues.
- Write about rights and responsibilities in your organization’s newsletter regularly.
- Support people to become politically active through voting, writing letters to the editor, and working with or meeting with their legislative representatives at all levels of government.

The Illinois department of Human Services requires that individuals who participate in service and support programs be specifically informed of the following rights:

- The right to remain in the adult day and residential program unless they voluntarily withdraw or meet criteria set forth in IDHS Rule 115, 119, and Rule 132.
- The right to contact the Guardianship and Advocacy Commission.
- The right to contact Equip for Equality.
- The right to contact the agency Human Rights Committee.
- The right to contact the Department of Human Services, or the Department of Human Services Office of the Inspector General.
- Any individual, upon request, will be assisted to contact the above agencies, if needed.
- The right to be free from abuse, neglect, exploitation, including financial exploitation, corporal punishment, or seclusion.
- The individuals or guardians shall be permitted to purchase and use the service of private physicians and other mental health and developmental disabilities professionals of their choice, which shall be documented in the services or treatment plan.
- Individuals shall not be denied, suspended, or terminated from services or have services reduced for exercising their rights.
- Individuals maintain all rights enumerated in chapter two of the "Mental Health and Developmental Disabilities Code." [405ILCSS], as well as the right to have disabilities accommodated as required by the Americans with Disabilities Act [Pub. L. 101-336], section 504 of the Rehabilitation Act [29 U.S.C. § 701] and the Human Rights Act[775 ILCS 5].
- Individuals have the right to confidentiality as expressed in the "Mental Health and Developmental Disabilities Confidentiality Act" [740ILCS110] and HIPAA [45CFR160 and 164].
- Individuals have the right to present concerns and to appeal adverse decisions of the provider up to and including the executive director to meet the criteria set forth in IDHS Rule 115, 119, and 132.
- The right to contact the public payer and to be informed on the grievance process used by the public payer.
- The right to receive all services in the least restrictive setting.

How might the following situations lead to unintended rights restrictions?
4 roommates-1 telephone
2 ladies live together and 1 has very restrictive diet due to serious health concerns
Hoarding
A person was found guilty of theft from Walmart
2 roommates-1 has a history of trying to harm herself

Discuss your Agency's specific rights statement.

Rights and Risk

Anyone who leads a life of dignity and meaning takes risks. Each of us, in the pursuit of jobs, our personal and romantic relationships, our leisure activities, and our adventure has stepped into the unknown and risked failure, rejections, and even our physical well-being. Anything any of us have ever accomplished has come from some level of risk-taking. The benefits of succeeding in these situations, or learning from our mistakes, are a crucial element in our development as independent people.

People who work and live with individuals with disabilities often try, usually with the best of intentions, to eliminate all of the risks and prevent any opportunities for failure in these individuals' lives. Some will even go to great lengths to prevent even minor failure, such as not allowing an individual with a developmental disability to lose at a board game. What can result is a life where an individual has never been tested, has never had the opportunity to grow, has never experienced the satisfaction of achieving something that was not certain to be achieved from the beginning.

Allowing individuals to take risks and step into the unknown is part and parcel with treating them with dignity. This is not equivalent to encouraging recklessness; allowing risk does not mean being unsafe or setting people up to fail. Rather, by supporting individuals in prudent risk-taking and utilizing the wealth of teaching opportunities it unearths, we can bring meaning into peoples' lives. Providing them with the opportunity to try new things, test their limits, explore new relationships and discover capabilities they never knew they had will help them to achieve goals that enrich their lives.

Imagine for a moment what it would be like if you were never allowed to take risk. Imagine someone else making all of your decisions for you, having the last word on what your life's experiences would be.

Learned helplessness can occur when decisions are made for people all the time. It can also increase the risk for sexual and domestic violence. How can you be sure to avoid learned helplessness while still protecting people from harm?

With rights comes responsibility. Discuss citizen responsibilities associated with the situations below.

Having a cell phone
Voting
Having a debit card
Driving a car
Dating

Guardianship

A guardian is a person, institution, or agency appointed by the Probate Court to manage the affairs of another, called the ward.

Who may have a guardian appointed to manage his/her affairs?

The law presumes that an adult eighteen years of age or older is capable of handling his/her own affairs. A guardian may be appointed to serve as a substitute decision-maker if a person is disabled because of:

- Mental deterioration
- Physical incapacity
- Mental illness
- Developmental disability

The disability must prevent the person from making or communicating responsible decisions about his/her personal affairs. A guardian may also be appointed if, because of “gambling, idleness, debauchery, or excessive use of intoxicants or drugs,” a person spends or wastes his/her estate so as to expose himself/herself or his/her family to want or suffering. In either case, guardianship may be necessary to protect the person and to promote the interests of others, such as service providers or creditors.

If is especially important to note that the parent of a child with a disability does not automatically become the child’s guardian when the child turns 18 simply because the child has a disability. Guardianship must be appointed. Some parents/families are surprised to learn this when their child turns 18.

Guardianship Process

Before starting a court proceeding, one must obtain a report certifying that the person has a disability and needs a guardian. A pre-printed form for the report can usually be obtained from the Probate Clerk of the court where the guardianship proceeding would take place. This is the court in the county where the person with disabilities resides. If the court does not have a pre-printed form, an attorney should be consulted. The report should be completed and signed by a licensed physician and any other professionals who are familiar with the person with disabilities. One or more of the persons who sign the report may be needed later to testify in court. It is important that the report contain all of the information required by paragraph 11a-9 of the Probate Act:

- Description of the nature and type of the respondent's disability, and an assessment of how the disability affects the ability of the respondent to make decisions or to function independently.
- Analysis and results of evaluations of the respondent's mental and physical condition and, where appropriate, educational condition, adaptive behavior and social skills, which have been performed within 3 months of the date of the filing of the petition.
- Opinion as to whether guardianship is needed, and the reasons therefore.
- Recommendation as to the most suitable living arrangement and, where appropriate, treatment or habilitation plan for the respondent and the reasons therefore.
- Signatures of all persons who performed the evaluations upon which the report is based, one of whom shall be a licensed physician and a statement of the certification, license, or other credentials that qualify the evaluators who prepared the report.

The more detailed the report, the more likely it will contain all of the information legally required for the court's decision. Since many Illinois physicians are unfamiliar with limited guardianship, it is important for the petitioner or his/her attorney to fully explore the potential for limited guardianship in each case regardless of the initial recommendation of the physician. Total (plenary) guardianship should only be used when the person with disabilities is so incapacitated that he/she truly cannot make any decisions himself/herself.

The report should accurately reflect the skills and abilities of the person as well as deficits and problems. It is up to the petitioner to assure that this is done; it may be necessary to have other professionals contribute to the report if the physician is not familiar with all aspects of the person's life, or if the nature of the disability is outside the physician's area of expertise.

Attorney Representation and Other Protections

Although an individual seeking guardianship for another may do so without the use of an attorney, the advice of legal counsel may be beneficial. The involvement of an attorney can be helpful where the alleged person with disabilities objects to guardianship or where complicated personal or financial issues are presented to the court. When a person opts to petition for guardianship without representation by legal counsel, a regional Office of State Guardian attorney, or a legal assistance agency may be consulted, in order to learn about specific practices or requirements in a particular court. In additional, the clerk of the court should be consulted to obtain copies of local court forms, and to learn about the scheduling of guardianship cases.

A person facing guardianship adjudication has the right to a court appointed attorney and a trial by a jury of six persons. An individual facing guardianship adjudication also has the right to request an independent medical evaluation, which must be paid from the funds of the alleged person with disabilities.

Can Guardianship Be Used In Case of Emergency?

Yes, when the court determines that emergency protection is warranted, a temporary guardian may be appointed. If there is an emergency requiring a guardian to be appointed before the hearing on the guardianship petition can be completed, one can ask the court to appoint a temporary guardian until the hearing.

How Does One Assess That a Person May Be In Need Of Guardianship?

The fact that a person has a mental disability does not automatically dictate a need for guardianship. The test for determining the need for guardianship focuses on the ability of the person to make decisions and to properly communicate decisions once made. Making incorrect or ill-advised decisions on a periodic basis is not the test. Rather, it is an inability to engage in the decision-making in the first place, which is important. A practical set of questions that may be addressed are as follows:

- Does the person understand that a particular decision needs to be made?
- Does the person understand the options available in any decision?
- Does the person understand the consequences of each option?
- Is the person able to properly inform appropriate parties once the decision has been made?

The inability to make sound decisions about where to live, where to work, and how and when to seek medical care or other professional services, how to properly care for dependents, and how to purchase items like food and clothing is an indication that a person may be in need of some guardianship services.

What might you do in preparation for recommending the need for a guardian?

Human Rights Committees

Human Rights Committees (HRC)

Human Rights Committees are typically internal committees that serve as a review mechanism for issues surrounding the protection and maximization of rights of people receiving services. These committees do more than endorse/reject restrictions, limitations and interventions. They have the skills and abilities to function as an administrative arm that makes the leadership aware of instances of less desirable practices are occurring.

Discuss specific information regarding Agency HRC policy and practice. Be sure to outline the role of the QIDP during your agency HRC meetings.

Potential Limitations on Access:

- To personal possessions (money, mail, clothing, cigarettes)
- To personal or public space (locked areas)
- Food or drinks
- Activities
- Friends, family, children, significant others
- Community services

Are there legitimate reasons to restrict a person’s access to possessions?

Potential Limitations on Movement:

- Bed rails
- Mitts
- Belts (gait belts, seatbelts, on wheelchairs, etc)
- Therapeutic holds/escorts (Safety Care techniques)

Discuss why the use of protective equipment would be considered a rights restriction.

Medication:

- Psychoactive drugs and medications used for behavioral control
- Birth control pills
- Sedation

Rights restrictions must be temporary. Discuss how the need for medications might be reduced or removed and the associated consequences.

Medical Procedures that May Require Review:

- Multiple tooth extractions
- DNR orders
- Feeding Tubes
- Helmets
- Braces, splints for behavior control (arm tubes, mitts)

Discuss the decision making process when a person disagrees with a doctor's recommendation.

Other examples:

- Guardianship concerns
- Research projects
- OIG reportable incidents; suspicious incidents, etc.

What "barometers" might you use to guide your response to any of these issues?

Prevention of Abuse and Neglect

The Illinois Administration Code Title 59, Part 50 is the foundational document that defines requirements for both providers and support workers regarding allegations, suspicions or information surrounding abuse and neglect of people served. The Administrative Code can be found at www.ilga.gov. The Office of the Inspector General (OIG) provides training to the staff of IDHS facilities, community agencies, and other state agencies and entities. Training must occur upon hire and biennially. Training materials for Rule 50 can be found on the IDHS website.

Use IDHS materials for detailed discussion of the administrative code.

Open and Honest Dialog about Abuse and Neglect

Talking and thinking about abuse, neglect and exploitation are essential components in establishing a culture that eliminates abuse and neglect to the greatest degree possible. Working in the disabilities field can be inspiring and fulfilling but at times can also be frustrating and challenging. There are times when things can go wrong, but, abuse and neglect are not actions that have to occur in a workplace. An organization can have a positive, supportive culture in which it is far more difficult for abuse to occur. Most staff are not abusers, but they are also not superhuman. Proactively working towards a culture of respect support, and openness <u>can</u> work to eliminate or decrease the likelihood of abuse or neglect, giving people with disabilities the highest quality of support and services possible.

One means of facilitating open and honest dialog about abuse and neglect prevention is the *Dialogue Deck on Abuse and Neglect Prevention.* Written thoughtfully and specifically for provider agencies, it establishes a firm foundation on which to base an abuse prevention program.

The *Dialogue Deck* is designed as a learning game for those who support people with developmental and intellectual disabilities. It is intended to help work groups share their knowledge and ideas about quality supports and services, thus helping to prevent the mistreatment of vulnerable people in their care. Discuss the following scenarios and talking points taken from the Dialog Deck.

Why is the risk for abuse or neglect of persons supported greater during transportation between sites and activities?

- Many people with disabilities have difficulties in dealing with changes in routine and transitions can be particularly challenging.
- Having what is sometimes a sizable number of people in the small, confined space of a vehicle can be stressful for some, creating anxiety, leading to aggressiveness and/or frustration on the part of both staff and people supported.
- Poor driving conditions, construction, excessive traffic, hot/cold weather, smells, vehicle fumes, loud noises, fear/anxiety, and unfamiliar people/staff can all contribute to the uncertainty of transportation time.
- Some residential and day programs have poor relationships with each other creating animosity among staff, leading to increases in pressure, anxiety, and lack of patience during times of transition.
- Staff at the day or vocational site are at the end of what could have been a very long, tiring, demanding shift – resulting in less patient interactions.
- Staff may have isolated access to the individual which increases risk of abuse

<u>Takeaways:</u>

- Staff are often in a hurry at this time of day. Why is this? What can agencies do to make this a more relaxed part of the day and eliminate some of the “hurry?”
- In some instances, people supported simply don’t want to go to the intended destination. People may experience motion sickness or other “physical” problems during vehicle rides.

- Agencies can assess any possible improvements they could make to this part of the day due to its potential high incidences of abuse. This could include a higher staffing ratio at this times, ensuring supervisors are available, easing of time schedules, or other ideas which contribute to a more relaxed and supportive atmosphere.

In what subtle ways can staff intimidate people supported?

- To intimidate means to frighten or scare. Intimidation can take on many forms – verbally/non-verbally and situational - some ways are very subtle in nature.
- To intimidate a person means scaring them into doing something they may not want to do or stopping them from doing something.
- To intimidate means creating a situation in which someone does not feel they can disagree with another without negative consequences.
- To intimidate someone means creating a situation in which one person has significantly more power and is using this advantage to make the other person feel less powerful.
- To intimidate means refusing to eliminate what someone might interpret as threatening or domineering behavior.
- Intimidation can occur verbally – when a person frightens another by saying something in a loud tone of voice.
- Intimidation can occur non-verbally – when a person attempts to "physically" frighten another by the way he/she looks at the person supported, the way a person positions his/her body, etc. (Example: Physical proximity – standing too close – within the person's personal space.)
- Intimidation can also occur through situation manipulation which results in feelings of discomfort for the person. (Example: a person creates an culture of mistrust)
- Results of intimidation: feelings of fear, mistrust, loneliness, powerlessness, etc.

Takeaways:

- People who have been intimidated throughout their life may feel intimidated more easily than people who haven't had this life experience. To a vulnerable population such as those with disabilities, actions such as the following can be intimidating:
    - Walking too quickly toward the person
    - Talking too loudly
    - Talking sternly

Personal Finances

Financial issues can't be escaped by anyone in our society. People with disabilities often need assistance in managing their money and their government benefits. This section will discuss many of the considerations that will require your attention for the people you serve including:

- ABLE (Achieving Better Life Experience) Act
- Social Security Representative Payee
- Spend Down/ Trust Fund
- LINK/SNAP
- Banking

The ABLE Act

The ABLE Act authorizes the creation of a new type of tax-free savings account that uniquely benefits people with intellectual and developmental disabilities. As long as the account is used to pay for approved special needs goods and services, both the growth of the account and the withdrawal of the money from the account are tax-free. The timing for the availability of ABLE accounts will vary from state to state.

The basic ABLE account guidelines are as follows:

- A limit of one ABLE account per individual
- Eligible individuals must have received their disability diagnosis prior to turning age 26
- $14,000 annual maximum contribution limit
- Tax-free growth of investments
- Tax-free distributions for qualified disability expenses
- Qualified disability expenses include: education, housing, transportation, employment support, health and wellness, assistive technologies, and miscellaneous expenses including legal fees, funeral and burial expenses and financial management and administrative fees
- Distributions must be reported
- Investment within ABLE accounts can be adjusted no more than twice per year
- Account balances over $100,000 will result in forfeiture of Supplemental Security Income (SSI) benefits until the account drops back below the threshold
- Medicaid benefits will not be impacted regardless of the size of the account

- State Medicaid payback provisions are identical to those in place for self-settled supplemental needs trusts and pooled trusts
- Rollovers to other ABLE accounts or 529 Plan accounts (rollover may be taxable if made to a 529 Plan)
- Contributions are protected from bankruptcy of parent or grandparent (if made 365 days prior to bankruptcy filing)

While the Act is not a panacea for saving for the costs associated with raising a child with intellectual/developmental disabilities, it gives families another weapon for battling the challenges they face.

The new ABLE accounts will be easy to open, have low operating costs, provide for tax-free investing, and allow for savings to accumulate while the family gets a better handle on what future expenses lay ahead.

Representative Payee

When a person receiving Social Security or Supplemental Security Income (SSI) is not able to manage his or her money, a representative payee can help. Currently, more than seven million children and adults who receive monthly checks get help from representative payees.

Representative payees help people (beneficiaries) by making sure their needs are met. Some of these needs include making sure the housing and utilities are paid on time, food is available, medical and dental needs are met, clothing is purchased and personal care items are provided. Payees are not the same as legal guardians who make decisions about all matters. Payees only have the responsibility of making money-related decisions.

Representative Payee Responsibilities:

Once the Social Security Administration selects the applicant to be a representative payee, the payee must make sure the beneficiary's day-to-day needs are met. As a payee continues helping, they will be asked to report any changes that could affect the amount of money the beneficiary is due. This list includes some examples of things that may affect the benefit amount. They should report when the beneficiary:

- Moves
- Starts or stops working
- Has a medical condition that improves
- Starts receiving another benefit type or the amount changes
- Goes to jail for a crime that carries a sentence of more than one month
- Is a child and custody changes or an adoption takes place
- Is a stepchild and the parents' divorce
- Gets married
- No longer needs a payee
- Dies

Payees must also tell the SSA if they are no longer responsible for the beneficiary, they move, they no longer want to be payee, they are convicted of a felony, or if they have violated a condition of their probation or parole.

Responsibilities of Reporting:
In addition to the requirements listed above, there are special reporting requirements for payees of beneficiaries getting SSI benefits. They should report when the beneficiary:

- Moves to or from a hospital, nursing home, or correctional facility or other institution.
- If married, when the couple separates or resumes living together.
- Has a change in income or resources
- Someone moves into or out of the beneficiary's house

If the representative payee fails to report any of the actions described above to Social Security, the beneficiary may be paid too much money. In that case, the payee may have to return the money the beneficiary was not due and payments may stop. If Social Security determines the representative payee intentionally withheld information in order to continue receiving payments, the representative payee may be criminally prosecuted. Criminal penalties may include fines and imprisonment.

Representative payees for SSI recipients should be aware that savings and other resources are limited to $2,000 ($3,000 for a couple) under the SSI program. Keep in mind that interest on savings counts toward that limit.

An individual has the right to receive their own Social Security check unless SSA has reason to believe they may spend their money in a way that might hurt them.

If your client has a representative payee because of a physical or a mental disability, in order to become their own payee, they must show SSA that they are now mentally and physically able to handle their money themselves. Individuals need to provide:

- A doctor's statement that there has been a change in their condition and that the doctor believes they are able to care for themselves; or
- An official copy of a court order saying that the court believes that they can take care of themselves; or
- Other evidence that shows their ability to take care of themselves.

<u>Note</u>: Be advised that if SSA believes their condition has improved to the point that they no longer need a payee, it may reevaluate their eligibility for benefits.

What is a "Trust Fund?"

A nursing home "resident trust fund" is an optional account that consists of the resident's money. This account is managed by the nursing home on behalf of the resident and is used for expenditures. As a Q, you might hear about "trust fund" from individuals who live in ICFs/DD or in CILA homes.

The resident who is on Medicaid is allowed to keep $30.00 per month and there is no limit to how much can be in a residents trust account. When a resident is discharged from the facility, the facility must return the remaining money from the residents trust account to them or their responsible party within 30-days.

Individuals usually refer to the $30 cash/spending money they receive on designated days during the month as "getting my trust fund."

What is a Medicaid Spend-Down?

For many people who cannot afford medical care, the Medicaid Spend-Down program in Illinois can help. The program is difficult to understand. Here are answers to some common questions about the program. However, to get answers about an individual's specific situation contact your local public aid office.

What is a spend-down?

A spend-down is like a deductible under a regular insurance policy. The spend-down amount is the amount of medical bills that IDHS will *not* pay each month. The individual must have medical expenses that equal the spend-down amount before they get Medicaid coverage for their medical expenses just as you have to meet the deductible before insurance will pay. For example, if the spend-down amount is $50 per month, an individual is eligible for Medicaid for the month once they have medical expenses that total $50. Examples of medical expenses that can be used to meet the monthly spend-down include payment for medications, doctor's visits, and blood tests.

What is Pay-in Spend-down?

In general, Aid to the Aged, Blind and Disabled (AABD) community MANG (Medical assistance no grant) clients also have the option to "pay" their spend-down amount each month. This is done instead of, or in addition to, submitting medical receipts.

How do individuals meet their spend-down amount?

There are 3 ways to meet the spend-down:

- use medical bills and receipts
- "pay-in" the amount of your spend-down
- use some medical bills and receipts and pay-in the rest

Individuals meet the spend-down amount by having medical bills that equal their spend-down amount. They don't need to pay the bills to have them count toward the spend-down. The bills can be old or recent.

You can assist individuals with spend-downs by reminding them to get copies of all medical bills and get receipts for prescription drugs and to ask for and keep receipts for transportation expenses to and from medical appointments (if any). Individuals need to show their bills to their caseworker at the Department of Human Services, so it is very important to keep them together and organized. Many agencies have a staff person who assists with this process.

What are SNAP and Link?

A LINK Card (they are blue).

The Supplemental Nutrition Assistance Program (SNAP) (formerly Food Stamps) helps low-income people and families buy the food they need for good health.

Benefits are provided on the electronic card which is accepted at most grocery stores. The program is managed by the Food and Nutrition Service (FNS) of the United States Department of Agriculture. The Department of Human Services administers the program in Illinois.

Who can receive these services?

Most households with low income can get SNAP benefits, including individuals who receive home-based services and individuals who live in CILAs. The rules are complex, so all of the details are not identified here. The most important factors which determine the amount of, and eligibility for, SNAP benefits are:

- income and expenses
- the number of persons who live and eat together

SNAP benefits **can** be used to buy:

- any food or food product for human consumption
- seeds and plants for use in home gardens to produce food

SNAP benefits **cannot** be used to buy:

- Hot foods ready to eat
- Food intended to be heated in the store
- Lunch counter items or foods to be eaten in the store
- Vitamins or medicines
- Pet foods
- Any nonfood items (except seeds and plants)
- Alcoholic beverages or tobacco

How to use the Illinois Link card
The Illinois Link card can be used at the grocery store to spend SNAP or cash benefits. The Illinois Link sign will be located in the windows or on the doors of the grocery store if that store accepts the Illinois Link card.

The steps below explain how to assist an individual to use their Illinois Link card.

1. At the checkout lane, the cashier is told that the Illinois Link card is being used and which account to use - the SNAP or cash account.

2. The individual, or the cashier, will scan the card through the Illinois Link terminal. If the card cannot be scanned, the cashier can manually type in the card number on the terminal to complete the purchase. ***Note:*** If the individual has too many manually entered transactions in a row, the card will automatically be replaced. The old card can still be used until the new card is received.

3. The individual, or the cashier, enter the amount of purchase or the amount of to be withdrawn.

4. The 4-digit PIN is entered. If the incorrect PIN is entered four (4) times in a row, the benefit account is "frozen". The Illinois Link card will not be able to be used until the individual gets a new PIN.

5. When the purchase or withdrawal is complete, the terminal prints a receipt with the name and address of the store, type of transaction, date of transaction, the amount of purchase or withdrawal, and the balance left in the account(s). The receipt should be saved to help keep account balances current.

6. There are no requirements for a minimum amount of a purchase or a maximum number of times the card can be used.

7. If coupons are used, the coupon amount is taxed and the tax cannot be paid with SNAP benefits.

Recommended Reading & Resources

Although we will try to cover a great deal of material with you today in class, the topic of advocacy, rights, and resources is a broad one that requires continued study and attention throughout your career. We recommend the following resources as good places to start with regard to furthering your knowledge and understanding of these important topics.

- Dialog Deck and Facilitator Guide, HighTide Press.
- Human Rights Committees, 3rd Edition, Staying on Course with Services and Supports for People with Intellectual Disabilities by *Steve Baker and Amy Tabor*
- Scanning the Horizon, Using Organizational Data to Prevent Abuse, Neglect and exploitation of People with Intellectual Disabilities by *Steve Baker and Amy Tabor*
- Money Smart by *Ted Hunter*
- The Principles and Practices of Universal Enhancement by *Tom Pomeranz*
- Universal Declaration of Human Rights of the United Nations
  http://www.un.org/en/documents/udhr/

For information on Self-Advocacy, you can view:

- "We Have Choices"
  A 29-minute documentary on individuals with developmental disabilities across New York state who have used individualized supports in taking greater control of their lives.
  University of Minnesota
  http://rtc.umn.edu/rtcmedia/wehavechoices/
- The Council on Quality and Leadership
  http://www.c-q-l.org/resource-library
- Guide for Starting Empowerment Groups
  www.illinoisimagines.org

Appendix A

Relevant Contacts

Guardianship and Advocacy Commission
Human Rights Authority
Central Intake (866) 274-8023 (866) 333-3362 (TTY)
Chicago/South Suburban Regional Authority (Will, Cook, DuPage)
P.O. Box 7009, Hines, IL 60141
Metro East Regional Authority (St. Clair), Pine Cottage
4500 College Avenue, Alton, IL 62002
Peoria Regional Center
401 Main Street, Suite 620, Peoria, IL 61602

Equip for Equality
Chicago (312)344-0022 (800) 537-2632 (800) 610-2779 (TTY)
Chicago
20 North Michigan Ave, Suite 300, Chicago, IL 60602
Central Illinois
1 West Old State Capital Plaza, Suite 816, Springfield, IL 62701

Illinois Department of Human Services
Customer Help Line (800)843-6154 (800) 447-6404 (TTY)
Chicago
401 South Clinton Street, Chicago, IL 60607
Springfield
100 S. Grand Avenue East, Springfield, IL 62762

Illinois Department of Human Services
Office of Inspector General
(800)368-1463

(for behavioral health participants)
Office of the Inspector General
Madden M.H.C.
(800)368-1463

Appendix B

Self-Advocacy Illinois

The Riot!
http://www.theriotrocks.org/

Illinois Self-Advocacy Alliance
www.selfadvocacyalliance.org/

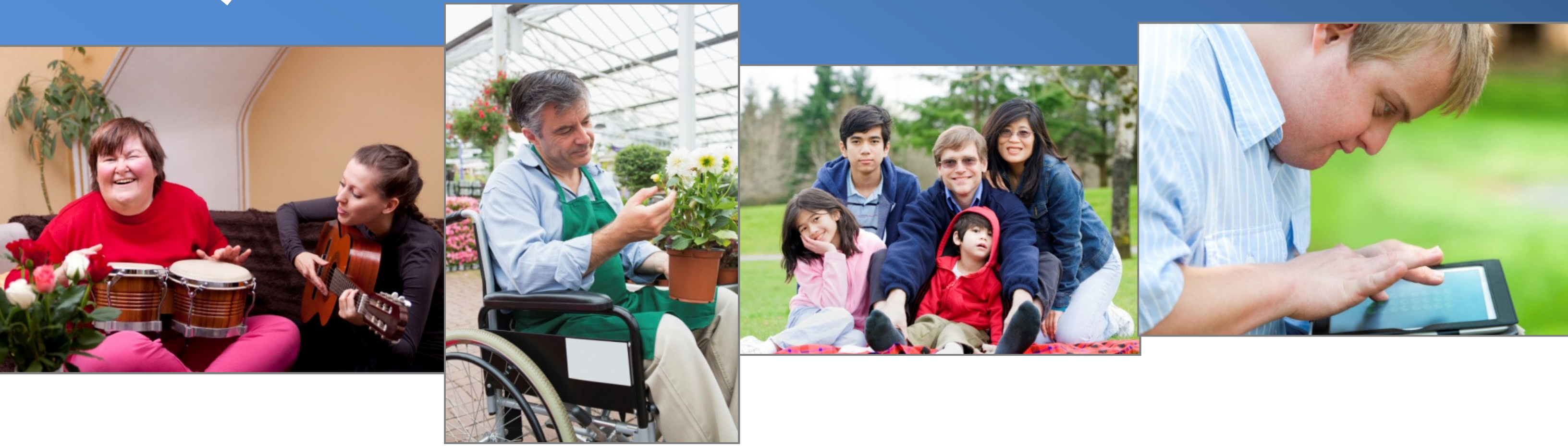
Self-Advocates Becoming Empowered (SABE)
http://www.sabeusa.org/

Advocating Change Together (ACT)
http://www.selfadvocacy.com/

People First of Illinois
www.peoplefirstofillinois.com

Disability Scoop
info@disabilityscoop.com

QIDP Professional TRAINING



Illinois Department of Human Services

- Module 1: Introduction to the World of the QIDP
- Module 2: Leadership and Communication
- Module 3: Behavioral Supports
- Module 4: Person Centered Planning
- Module 5: Record Keeping
- Module 6: Advocacy, Rights, and Resources
- Module 7: Environmental and Safety Supports
- Module 8: Medical Supports
- Module 9: Rules and Regulations

Module Overview

Module 7 Introduction

Why are environmental and safety issues important to you, as a QIDP?
IDHS and IDPH regulations include many items on the “physical plant” elements of the environment in which agencies provide services. QIDPs have the primary responsibility for maintaining the safety and security of many of those elements. Agencies that provide residential services are either homeowners and/or landlords, and as such have to keep dwellings safe and up to code.

Objectives
Participants will be able to:

- Describe the characteristics of a quality home or day program environment.
- Identify adaptive equipment and devices used to enhance independence.
- Explain the importance of regular household maintenance.
- Identify improvements for making the environment safer for individuals, staff, and visitors.
- Outline general weather safety information and tips.
- Identify adaptive equipment and devices used to enhance independence.
- Describe the process of repair and maintenance on organizational facilities.
- Recall the dangers associated with various household products.
- Suggest protective measures for general household safety.
- Describe guidelines for fire and other disaster drills.
- Identify common fire hazards.
- Recognize the importance of food safety as it affects foodborne illnesses and overall health.
- Collect individual information using the risk assessment tool utilized by the agency.

THE ENVIRONMENT

"I try to create homes, not houses."

- Louis Kahn

Safety should be a concern in every environment. While accident-proofing every aspect of your home or residential program is impossible, you can make simple improvements that will make the home safer for everyone. Mobility problems and hearing, learning, or seeing disabilities can add complications.

Although safety is imperative in our living environments, you must never forget that as a QIDP, you must assure that the individual's home environment is aesthetically pleasing and has a home-like atmosphere.

When attempting to improve household comfort and safety, it is important to consider the following:

- Quality of Home Environment
- Accommodations and Adaptations
    - Adaptive Equipment
    - Adaptive Devices
- Weather Safety
    - Heat Related Dangers
    - Tornados
    - Thunderstorms and Lightning
- Household Safety
    - General Maintenance
    - Slips, Trips, and Falls
    - Water
    - Household Products and Poison Prevention
- Fire Safety
    - Fire Hazards
    - Evacuation Drills
    - Electrical Hazards
    - Carbon Monoxide
- Food Safety

A Quality Home Environment

An important part of your role as a QIDP is to ensure that the people you help support live in an environment that ensures quality surroundings - a type of home that **you** would want to live in.

When thinking about the 'quality' of a home environment, one of the first things we think about is the aesthetics. Aesthetics include such things as light, color, temperature, humidity, scents, sounds, etc. Everyone is affected by their environment; dark, dingy rooms will affect even the most cheerful person. Quality also includes environmental cleanliness and safety for everyone.

Quality should be viewed in terms of what the individual experiences in their home/living arrangement. Of course, needs and preferences vary from person to person, so it's important to know the needs of the people you help support and involve them in planning process when designing the environment.

As a group, discuss the different characteristics that you feel make up a quality home. Use the space below to record your own thoughts and those of the group.

-
-
-
-
-
-
-

Accommodations and Adaptations

A quality home must be environmentally safe and appropriate to the needs of the individual. Due to the varying abilities of the individuals we help support, various types of accommodations and adaptations may be necessary to enhance independence.

Adaptive Equipment

Adaptations are objects or devices that are made or changed specifically to help an individual accomplish a task or skill. All of us use adaptations in our lives. The spell-check on our computer is an adaptation, as is the timer we use while cooking. Adaptations allow us to bypass sensory, physical or cognitive challenges in order to participate in activities. Some ways to use adaptations are:

- Adapting Environments
- Adapting Devices
- Providing Physical Supports

Home Modifications

Home modifications can be an important tool to maximize safety as well as independence. Examples of home modifications can include:

- Entrances: Constructing ramps, building zero-step entries, or widening doors
- Bathrooms: Installing grab bars, showers with anti-scald devices, shower seats, or walk-in bathtubs
- Kitchens: Lowering counters, installing revolving shelves, or building sinks with lever handles as opposed to knobs
- Stairs: Installing an elevator or stair glide

Adaptive Devices

In some cases, meal intake and nutritional status can be improved through the use of adaptive eating equipment (cups, utensils, and plates) that have been modified to allow for greater independence. Occupational Therapists can decide who can benefit from adaptive eating equipment. Once an order is written for adaptive equipment, it is the responsibility of staff to ensure that the equipment is provided for use at each meal. Examples of types of adaptive eating equipment can include:

- Scoop plate
- Plate guard or lipped plate: Used in cases of weakness or poor hand coordination
- Rocker Knife (Cuts by rocking rather than sawing): Used by those with CVA (Cerebral Vascular Accident), those with use of only one hand, poor coordination, and tremors
- Weighted utensils: Used for Parkinson’s and other conditions resulting in tremors
- Utensils with built-up handles: Used for those with weak grip, arthritic hands, and tremors
- Non-slip handles: Used for those with decreased fingertip sensation or poor grip
- Angled utensils: Used for those with poor range of motion, or who are unable to get utensil to mouth

SCENARIOS

Adapting the Environment

Scenario 1

Angela is a young woman that you help support who has significant vision problems. She has difficulty accomplishing visual tasks, even with prescribed corrective lenses, but is able to accomplish tasks with the use of compensatory visual strategies and environmental modifications. She has recently moved into a new home and has expressed a strong desire to learn how to cook.

As Angela's QIDP, what low cost strategies or adaptations might you consider making in order to help her become more independent in preparing meals?

Scenario 2

Consider this same scenario for someone who uses a wheelchair.
What types of low cost adaptations or modifications could be made?

Weather Safety

Heat Related Dangers

Heat-related illnesses and deaths are preventable. People suffer heat-related illness when their bodies are unable to cool down properly, especially in high temperatures and high humidity. While all are at risk, the threat is increased for people with cognitive impairments, those taking certain medications, with acute/chronic illness, as well as the elderly and very young.

Sun Safety

With one in five Americans developing skin cancer, education about sun safety is a vital step toward reducing risk and improving public health. Overexposure to the sun's ultraviolet (UV) rays seriously threatens human health. Besides the immediate effect of sunburn, over time excess UV radiation can cause skin cancer, eye damage, immune system suppression, and premature aging.

Taking Precautions

- Be aware of the heat, and modify or reschedule outdoor activities accordingly.
- Drink plenty of fluids, limit caffeine, and eat well-balanced, light, regular meals.
- Wear loose fitting, lightweight, and light-colored clothing.
- Do not leave individuals unattended in a vehicle, even with windows down, no matter how brief.
- Establish a routine to be sure all occupants leave the vehicle when unloading. Check each seat for sleeping/reclining individuals.
- Prolonged exposure to the sun should be avoided by individuals with known sensitivity. Protective clothes, hats, sunglasses and sunscreen should be used when outside.
- Some medications can cause sensitivity to sunlight called **photosensitivity.** When photosensitivity is suspected, discuss a possible medication change with the doctor. This condition can result in:
    - A rash-like condition
    - Severe burns and skin cell damage
    - Sunlight intolerance
    - Eye pain

Storage and Summer Use of Medications

Some medications can become less effective when exposed to direct sunlight, heat, cold or moisture. Be especially careful during summer months to store medications properly.

General Storage Guidelines:

- Store medications that do not need refrigeration at room temperature below 86 degrees Fahrenheit
- Avoid storing medication in moist, humid areas
- Keep medication away from direct sunlight
- Store medications in their original containers

- Discard expired medications according to your agency policy. **When in doubt, throw it out**
- Medication may lose its potency because of improper storage or transport
- Medication should not be given when any of the following are observed:
    - A change in appearance or odor
    - A change in consistency (i.e. tablets that crumble easily or capsules that are stuck together or crack)
    - Liquid medications that become cloudy, thick or change from their initial appearance or consistency

Types of Heat-Related Illnesses

- Heat Exhaustion – A milder form of heat-related illness. Signs and symptoms include:
    - Heavy sweating, paleness, skin may feel cool
    - Muscle cramps, fatigue, weakness
    - Dizziness, headache, fainting, nausea or vomiting
    - Pulse rate may be fast and weak, but breathing may be fast and shallow

- Heat Stroke – This is a medical emergency. When a person's body temperature rises to a dangerous level, it can lead to vital organ damage and death. Signs and symptoms include:
    - An extremely high body temperature (above 103^{o}F)
    - Red, hot, dry skin and absence of sweating
    - Rapid, strong pulse rate, throbbing headache, dizziness, nausea or vomiting

  Immediate Steps to Take
    - Contact Emergency Medical Services immediately if heat stroke is suspected or person is exhibiting extreme symptoms or heat exhaustion
    - Get the person to a cool, shady area, and attempt to cool them down with cool water
    - Monitor body temperature
    - Give fluids if person is alert and able to swallow
    - Seek medical follow-up for milder heat-related illness as soon as possible

Tornado

Tornados are one of nature's most powerful destructive forces. They are capable of destroying structures, uprooting trees, and hurling objects through the air. Tornados are most common in the Plains States, so it is important to be prepared.

It may be helpful to know and understand the difference between a tornado warning and a tornado watch. A tornado watch means that tornados are possible and near the watch area. Be ready to act quickly if a warning is issued. A tornado warning is more severe. It means that a tornado has already been sighted or reported by weather radar. Take cover immediately following a tornado warning.

Tornado Safety Tips

- Discuss tornado safety with all members of the house
- Take shelter indoors – preferably in a basement, crawl space, or interior first-floor room or hallway
- Avoid windows and seek additional protection by getting underneath large, solid pieces of furniture
- To protect oneself from flying debris, cover the head with the hands or a blanket if possible
- Avoid automobiles or mobile homes
- Those caught outside should lie flat in a depression or other low ground and wait for the storm to pass
- Practice periodic tornado or disaster drills so everyone knows what to do if a disaster strikes

Insert agency specific information here.

Thunderstorms & Lightning

There are many hazardous conditions associated with thunderstorms. Rainfall can cause poor road conditions, hail can damage cars and windows, and lightning strikes can start house fires.

Thunderstorm Safety Tips

- Discuss thunderstorm and lightning safety with all members of the house
- Pick a safe place for members to gather during the storm
- Stay away from windows, skylights, and glass doors that could be broken by strong winds or hail
- Avoid taking a bath or shower
- Postpone all outdoor activities if thunderstorms are near or likely to occur

Household Safety

General Maintenance

Good preventative maintenance plays a major role in ensuring household systems continue to function effectively. Keeping up with regular home maintenance will keep you from future headaches and wasted money. General maintenance plans include regular testing and maintenance of the home's mechanical and safety systems that can pose a risk if not properly maintained.

Some examples of these systems include:

- Heating, Ventilation, and Air-Conditioning Systems
- Water Heater
- Water Softeners
- Fire Alarms
- Carbon Monoxide Detectors
- Fire Extinguishers

Every organization has its own process for repair and maintenance of their facilities. Spend some time reviewing your organization's policies and procedures concerning this issue.

Insert agency specific information here.

Slips, Trips, and Falls

Falls are the leading cause of injury and accidental death in older adults. In some persons with developmental disabilities, the degenerative changes seen in aging can occur as early as age 35. Falls can result in hip fractures, broken bones, and head injuries. Even falls without a major injury can cause an individual to become fearful or depressed, making it difficult for them to stay active.

Preventing Slips, Trips and Falls

The best way to prevent falls is to make changes in several areas, including taking a look at where the individual may be at risk. Sometimes making changes in the home, physical therapy/exercise, medications or daily activities can help mitigate the risk of falls.

Protection from Slips, Trips and Falls

Some considerations include:

- **Have good lighting**. Use bright light bulbs, and add lights that can be turned on by a switch near the doorway and close to the bed. Another option is to install voice or sound-activated lamps. Keep a flashlight at bedside. Use night lights.

- **Keep stairways safe**. Be sure that stairwells are well lit and have handrails on both sides. Fluorescent tape may be placed on the edges of the top and bottom steps.
- **Keep bathrooms safe.** Install grab bars beside tubs, showers and toilets. Use a rubber bath mat in the shower or tub. Consider using a shower chair in the shower.
- **Keep rugs in place**. Check that all carpets and rugs have skid-proof backing or are tacked to the floor, including carpeting on stairs. Place non-skid mats or carpet on all surfaces that may get wet.
- **Avoid clutter**. Keep rooms free of clutter, especially on floors. Keep cords and wires out of walkways. Arrange your furniture and other objects so they are not in walkways.

Emergency Response to a Fall Incident

Even with the best precautions, falls may still occur. The response to an individual's fall depends on the circumstances of the fall, the person's ongoing health status, and what injury the person appears to have sustained. If you observe someone who has experienced a fall, quickly assess the situation by listening, observing and asking questions. Follow necessary and appropriate protocols such as first aid or calling 911.

Water Safety

People can drown in lakes, oceans, swimming pools, whirlpools, bathtubs or showers.
Wherever there is water, there is risk.
Near drowning can cause serious impairments and/or brain damage. Be alert to these contributing factors:

- Inadequate supervision
- Seizure disorder
- Medical emergencies while in the water (heart attack/stroke)
- Use of medication
- Water conditions, including temperature and clarity; hidden objects

Before A Swimming/Water Sport Activity

- Assess each person's swimming abilities and the level of supervision needed. Know each person's health care needs, behaviors and other conditions which may impact their safety in the water. Make specific staff/individual supervision assignments; one to one supervision should be provided to people with seizure disorders and people who are not ambulatory.
- Use U.S. Coast Guard -approved person floatation devices (PFD) for people who cannot swim, those who have seizure disorders and those who are not ambulatory. PFDs must be properly sized and maintained to be effective; however, they are not a substitute for supervision.
- Establish a system for ensuring that the whereabouts of all individuals is known. Visual contact must be maintained with all individuals in the water at all times. Alert lifeguards to the special needs of individuals; ask lifeguards if the swimming area poses any special risks.
- Before individuals enter the water, assess clarity and temperature of the water, weather

conditions, and potential for overcrowding of the area. Provide supervision appropriate to the conditions found.

In The Water

- Do not rely upon lifeguards to provide supervision. Staff, who are responsible for individuals, must be directly supervising the individuals and must be in the water with them.
- Call for help at the first sign of trouble.
- Maintain visual contact at all times with individuals for whom they are responsible. Supervision of individuals must not be interrupted by assigned staff to perform other duties, such as escorting individuals to the bathroom.
- All rules of the swimming area should be observed.

Bathing

- Assess each person's needs for bathing supervision and assistance.
- Be aware of each person's health care needs which could impact upon their need for supervision when bathing. If supervision is required, never leave the person alone.
- Staff should ensure that all bathing supplies are available in the bathroom before assisting an individual with bathing.
- Know how to correctly operate all special tubs and bathing equipment.
- Showering is generally safer than bathing for people with seizure disorder.
- Water temperature in the house is at a safe level and should not exceed 110 degrees.

Household Products and Poison Prevention

Many of the products we use for housework, gardening, home improvement, or car maintenance contain hazardous materials. Accidental poisoning can be reduced by storing all medicines, including nonprescription drugs and cleaning products in their original containers away from high-traffic areas and out of the reach of those that cannot use them safely.

There are four ways that poison can enter the body:

- Swallowing
- Breathing
- Touching
- Injecting

Hazardous Product Labels

The Federal Hazardous Substances Act of 1960 established labeling requirements for consumer products containing hazardous substances. If a product has a hazardous substance, the front label must include a warning and a description of the hazard. Levels of hazards are identified by the following:

- Danger: Substances which are extremely flammable, corrosive or highly toxic
- Poison: Substances which are highly toxic
- Warning or Caution: Moderately or slightly toxic substances

Household products are hazardous if they are:

- Ignitable: Capable of burning or causing a fire
- Corrosive: Capable of eating away materials and destroying living tissue when contact occurs
- Explosive and/or Reactive: Can cause an explosion or release poisonous fumes when exposed to air, water or other chemicals
- Toxic: poisonous, either immediately (acutely toxic) or over a long period of time (chronically toxic)

Other cautions include:

- Post the Poison Control Center telephone number next to the phone.
Poison Help Hotline: 1-800-222-1222
- Read and follow directions on product labels
- Never mix two products together unless you are certain it is safe to do so
- Never mix bleach and ammonia
- Handle the product carefully to avoid spills and splashing. Close the lid as soon as the product is used. This will control vapors and reduce chances of spills. Secure lids tightly.

Emergency Response to a Poisoning Incident

In the event of a poisoning, immediately call the Poison Control Center and:

- Remain calm
- Have someone stay with the person
- Report what type of poisoning (brand name and label, if possible)
- Report the amount ingested (tell them if you don’t know)
- Report the age and weight of the person
- Report how much time has gone by since the incident occurred

Fire Safety

Identifying and removing fire hazards is the first step towards fire safety. Review the bulleted points below for general fire safety guidelines.

Fire Hazards

Below are some of the most common hazards which cause injuries or death related to fire:

- No means of appropriate exit
- Lack of escape plan
- Lack of escape plan knowledge
- No working smoke detectors
- Lack of fire extinguishers or knowledge of extinguisher use
- Flammable materials stored in unsafe locations
- Poor smoking habits

Fire Safety

- Regularly checking fire safety systems is an important part of this process. Smoke alarms and carbon monoxide detectors should be tested monthly; the batteries should be changed biannually.
- It is required that at least one carbon monoxide alarm is placed within 15 feet of every room used for sleeping.
- At least one fire extinguisher should be available in the residence; it should be inspected annually and replaced when necessary.
- It is beneficial to have a disaster preparedness plan in place; this plan should be reviewed with staff and individuals regularly.
- Make sure heaters and radiators are never too close to flammable objects such as draperies or bedding. Ensure that the people who live in the home and use space heaters or electric blankets are able to regulate temperatures and turn them off when they leave the room.
- Stay in the kitchen while cooking. If a grease fire starts, smother it with a lid or baking soda. Should a fire start in the oven, turn off the appliance and leave the door closed.

Discuss your Agency's fire and evacuation drill requirements for each program (e.g. ICFDD, CILAs, Day Programs, etc.)

Evacuation Issues

Most people are hurt or killed in a fire because they do not know what to do. People with developmental disabilities may not be able to take life-saving actions in a timely manner. They may wait for verbal instructions or simply wait to be rescued.

Be prepared for issues that may arise when planning and carrying out fire evacuation actions. These issues may include:

- Resistance or refusal to evacuate
- Attempts to wander back into the house
- Age or frailty making evacuation more difficult
- Reactions or behaviors that may make evacuating difficult
- The need for bed shakers for some individuals in order for them to respond.
- Staff and individuals do not assemble at a safe outside area
- Weather can cause reluctance or discomfort while outside

Fire Drills

When an alarm sounds for a fire drill or a real fire, follow the instructions provided by your agency. After a fire drill or an evacuation drill, everyone's response to the fire drill is reviewed and evaluated so improvements can be made in future drills or in the case of an actual fire.

- Write a drill schedule for the entire year, including the dates each type of drill should be run and on what shift it should occur.
- Follow up on any problems that may have occurred during the drill. Then check the documentation next month to see if they reoccur.
- If your system is hard wired to an alarm company, check with them for any reception problems.
- During a drill, practice what is written in the evacuation procedures. If they don't result in a successful outcome, evaluate the reasons and amend the procedures.
- Record actual time of day the drill began, the length of time it took to clear the site, and the time it took for all individuals to reach the agreed upon meeting place.
- If multiple individuals at the site need physical assistance, how and/or in what order are staff to assist.
- Conduct unannounced drills.
- When planning drills do so across shifts and during various activities.
- If your agency changes a procedure in writing in order to correct a problem, you are responsible for implementing that change.
- You may want to incorporate Rule language when writing policies and procedures.
- Whenever possible, teach individuals to use safety devices (drop down ladders, fire extinguishers, etc.) in the case that staff are unable to assist them in an emergency.

Electrical Hazards

- Avoid using extension cords
- Do not use appliances with frayed electrical cords
- When unplugging an appliance, make sure to hold the plug and not the cord.
- Turn small appliances off when not in use.
- Never touch appliances or switches with wet hands.
- Never nail or staple cords to walls or baseboards.
- Use only the sizes and types of light bulbs listed for your lamps so they do not overheat.
- Keep a bulb in all light fixtures (even a burned-out bulb) to prevent electric shocks.

Carbon Monoxide

Carbon monoxide (CO) is:

- A colorless, odorless, and tasteless gas or liquid.
- It results from incomplete oxidation of carbon in combustion.
- It burns with a violet flame.
- It is slightly soluble in water.
- It is soluble in alcohol and benzene.

Food Safety

Food safety is and should be a major concern. Foodborne illness causes millions of people each year to fall ill as a result of eating unsafe food. The Center for Disease Control (CDC) estimates that each year roughly 1 in 6 Americans (or 48 million people) get sick, 128,000 are hospitalized, and 3,000 die of foodborne illnesses. Foodborne illness is a disease that is carried or transmitted to a person by the food they consume. Examples of organisms that can cause a foodborne illness include E. coli, Salmonella, and Campylobacter. Sources of foodborne illness or "food poisoning" may be the food handler, the environment (such as a contaminated work surface), or the food itself.

Symptoms of Foodborne Illness include:

- Nausea
- Vomiting
- Abdominal Cramps
- Diarrhea
- Fever
- Reactive arthritis

The five keys to safer food are:

1. Keep hands, preparation areas, and storage areas clean
2. Separate raw and cooked foods
3. Cook all foods thoroughly
4. Keep food at safe temperatures
5. Use safe water and raw materials

Temperature

Refrigerator temperatures should be kept at a minimum of 40ºF or below. Freezers should be kept at 0ºF. Typically, when surveyor's complete site visits at CILAs and in Day Programs they check for the presence of a thermometer in any refrigerator or freezer that stores client food.

As a general rule, it's best to keep cold foods cold and hot foods hot. Avoid the "Danger Zone," a temperature range from 40 ºF – 140ºF, where bacteria are most likely to grow. Raw meat, poultry, dairy products, seafood, eggs, and produce are most susceptible to foodborne illnesses and should be handled with care and caution. Perishable foods should never be left out for longer than 2 hours. Always remember, "When in doubt, throw it out."

Utilize a food thermometer to guarantee foods are cooked to the correct temperatures. When raw foods are cooked to the proper internal temperatures, the bacteria can no longer survive. This best practice will ensure that raw, possibly contaminated foods are safe to eat.

Hand Washing

Everyone preparing food should wash their hands before handling or preparing food and after handling raw meat, touching an animal, blowing nose or sneezing, and toileting. Ensure plenty of soap and clean paper towels are nearby. Hands should be washed for a minimum of 20 seconds, or while singing the "Happy Birthday" song twice.

Avoid Cross-Contamination

- Separate raw meat, poultry, seafood and eggs from other foods in your shopping cart and grocery bags.
- Use a clean knife for cutting different foods (for example, use different knives for cutting meat, produce and bread).
- During food preparation, do not taste the food with the same utensil used for stirring.
- In the refrigerator, store raw meat separately from ready-to-eat foods.
- When grilling, always use a clean plate for the cooked meat.
- Don’t reuse marinades used on raw foods unless you bring them to a boil first.

Risk Assessment

The challenge for agencies/providers is to support each person so he/she can make their own decisions and choices while facing minimal exposure to risk of serious harm. The ability of the person to make informed choices must be balanced with a reasonably safe environment.

Risk assessment measures generally assess risk in the following areas:

- Community safety
- Health/Medical
- Sexuality/Relationships
- Abuse
- Financial exploitation
- Challenging behaviors
- Fire safety
- Personal care/ Daily living
- Police involvement
- Informed consent
- Home environment

It is the responsibility of all of us to assure that people with disabilities and their families are provided with access to adequate quality information in order to make appropriate decisions in areas affecting their personal lives.

As a QIDP you will likely be responsible for assessing risk and addressing limitations proactively and in a manner that maximizes safety, learning and independence.

Review your agency's practices regarding risk assessment.

Rights Restrictions

It's important to keep in mind that you may have rights restrictions to take into consideration with certain individuals in certain environments. For example, we can't just put alarms on doors just because an individual might have elopement issues. A door alarm (just like a bed or wheelchair alarm) is a rights restriction, and it's a restriction for every individual in the house, not just the individual we're concerned might elope. Similarly, some individuals with diagnoses like Pica or Prader-Willi Syndrome might eat non-food items that cause a life-threatening situation. However, we cannot just lock up all of the food in the house and put a lock on the refrigerator without getting approval to restrict the rights of all individuals in the home.

If you haven't already done so, make sure that you are familiar with your agency's missing person procedure, elopement procedure, and any rights restrictions that might already be in place in the environment in which you work that have to do with the house/facility itself.

Critical Incidents

The agency is required to have written policies and procedures for handling, investigating, reporting, tracking and analyzing critical events (sometimes called unusual incidents). You will need to know and understand your agency's policies regarding the following issues:

- Sexual Assault
- Abuse or Neglect
- Death
- Physical Injury
- Assault
- Missing Persons
- Theft
- Criminal Conduct

Review your agency's policy on critical incidents.

Universal Sign for Emergency

For individuals who are deaf and/or blind, receipt of an emergency message often involves diverse communication needs. Communication with individuals who are severely hearing and vision impaired can range from sign language near the person's face to sign language in the palm to words written on the palm with a finger.

The universal symbol for an emergency is a tactile symbol "X," "drawn" on the back of a person who is severely hearing and vision impaired by an individual who is alerting him or her.

This symbol is understood to mean that an emergency has occurred and that it is imperative for the individual receiving the message to follow directions and not ask questions.

Recommended Reading & Resources

Although we will try to cover a great deal of material with you today in class, the topic of environmental safety is a broad one that requires continued study and attention throughout your career. We recommend the following resources as good places to start with regard to furthering your knowledge and understanding of this important topic.

For more information on:

- Illinois State Law and Carbon Monoxide Detectors
  http://www.idph.state.il.us/public/hb/hbcarbon.htm
- First Alert: Fire Safety Video
  http://firstalert.co.uk/?page_id=90
- The Danger Zone
  http://www.fsis.usda.gov/wps/portal/fsis/topics/food-safety-education/get-answers/food-safety-fact-sheets/safe-food-handling/danger-zone-40-f-140-f/ct_index
- *Safe by Accident* by Judy Agnew and Aubrey Daniels

Appendix A

Safety Checklist

Fire Safety

__ Is there a means to exit?
__ Is the means of exit suitable for this individual?
__ Is there an escape plan suitable for the individual?
__ Does the individual know the escape plan?
__ Is there an alternate escape route?
__ Are there working smoke detectors? Are they in appropriate locations?
__ Are there fire extinguishers? Does someone know how to use the fire extinguishers?
__ Are flammables and combustibles stored in appropriate locations?
__ Is the individual a smoker?

Physical Hazards

__ Are there good housekeeping practices?
__ Are stairs free of obstacles?
__ Are the floors dry?
__ Are carpeting and rugs secured?

Chemical Hazards

__ Is the living area free from carbon monoxide?
__ Is the area free from radon?
__ Are cleaning compounds, pesticides and other chemicals properly stored?

Electrical Shock

__ Is the living area free from potential electrical shocks (e.g. frayed cords, overloaded outlets, water near electrical equipment, etc.)?

Food Service Sanitation Hazards

__ Are individuals and staff using proper personal hygiene?
__ Are foods stored at safe temperatures?
__ Are foods properly protected?

Pest Control Hazards

__ Is the living area free from evidence of roaches, rodents, flies, fleas, etc.?

Water Supply & Sewage Disposal

__ Is the water free from contamination?
__ Does water drain freely from sinks, tubs, showers, stools, etc.?
__ Is the septic system working?
__ Is the living area free from the presence or smell of sewage?

Any items not checked should be addressed immediately per your agency's policy and procedures.

QIDP Professional TRAINING

Illinois Department of Human Services

Module 1: Introduction to the World of the QIDP
Module 2: Leadership and Communication
Module 3: Behavioral Supports
Module 4: Person Centered Planning
Module 5: Record Keeping
Module 6: Advocacy, Rights, and Resources
Module 7: Environmental and Safety Supports
Module 8: Medical Supports
Module 9: Rules and Regulations

Module Overview

Module 8 Introduction

Why is this information important to you, as a QIDP?
The medical status of an individual can dramatically impact his/her quality of life. As a QIDP, you are responsible for coordinating and/or providing supports to enhance an individual's capacity for health and safety. When necessary, you will need to develop supports to fill gaps for an individual who cannot manage each of these independently.

Objectives

Participants will be able to:

- Identify and explain the components of a basic physical assessment.
- Recognize a potential emergency situation based upon an individual's characteristics and vital signs.
- Outline dietary restrictions and related diet plans that are common.
- Describe the dangers of PICA and suggest protocol for dealing with the disorder.
- Explain risk factors for the major health issues, including aspiration, dehydration, constipation, and epileptic seizures, commonly known as the Fatal Four.
- Demonstrate an understanding of the intervention strategies for the Fatal Four.
- Recognize bowel and urinary issue risk factors and treatment options.
- Classify the types and typical side effects of the medications usually prescribed to individuals with disabilities.

MEDICAL SUPPORTS

> "The human body experiences a powerful gravitational pull in the direction of hope. That is why the patient's hopes are the physician's secret weapon. They are the hidden ingredients in any prescription."
>
> ***–Norman Cousins***

When evaluating health services, it is imperative that you know the individual. A basic physical assessment needs to be done to provide a baseline. This establishes what is normal for the individual. Variations above or below the baseline range are indicators of potential problems or emergencies that may require interventions. Make sure the information is passed on to those that have a need to know such as staff, family and administrators.

For certain medical or behavioral situations, the team may recommend that a consultation by an expert is necessary. Be sure to know your agency policy on consultations. Any recommendation from a consultant that involves active treatment, therapy or a change in diet texture/order will usually require a physician's order before it is implemented.

Preparing For a Medical Appointment

Primary care physicians do not necessarily have education or experience working with people with intellectual and developmental disabilities. As a QIDP, there are many considerations for maximizing the time and benefit of physicians and other medical practitioners.

1. The decision regarding who should accompany the person should be based upon knowledge of the person, knowledge of the medical concern, comfort level of person, ability to articulate the concern and communicate with the physician.
2. Prior to the visit, talk with those involved in the individual's health care to identify any health concerns.
3. Tell the physician about all medications the person is taking. *It may be helpful to bring a list.*
4. Bring a written list of any concerns and questions you and/or the individual may have.
5. Make sure you understand what the physician is saying and don't be afraid to ask for clarification.
6. When the physician writes a prescription, ask any questions you may have about the medication.
7. Encourage the individual to ask questions and express concerns.
8. Ask for clear directions for follow up.

Nursing support varies from agency to agency and program to program. Review relevant material related to nursing supports and protocols for your agency.

Podiatrist

Diabetes can cause poor blood flow to extremities including the feet. Even the most minor cuts, abrasions and sores on a diabetic's foot can result in serious health complications. Given this, it is often best for people with diabetes to see a podiatrist.

Dentist

Poor dental care can be related to many health issues such as earaches, headaches, heart disease and poor nutrition.

Orthotist

Orthotists are concerned with managing body function with the use of splints, braces, orthotics and wheelchairs as directed by a health care specialist. They will also modify equipment to ensure a therapeutic and comfortable fit. Orthotists may come to the home to see individuals in their own setting or they may evaluate them in a clinic or hospital.

Splints, braces. wheelchairs, etc. are called "durable medical equipment" (DME) and are usually paid for by insurance plans. The need for DME should be assessed by occupational or physical therapists and constructed or modified according to the therapists' specifications.

Physical and Occupational Therapists

The physical therapist's duties may include:

- Assessing body movement and posture.
- Providing direct therapy.
- Determining the need for adaptive and protective equipment (They may also assist in the design and repair of such equipment)
- Assisting in training the individual and others in:
    - Proper positioning
    - Range of motion
    - Body mechanics to maximize mobility and flexibility

The occupational therapist's duties may include:

- Assessing motor skills needed to carry out activities of daily living.
- Assessing hand-to-mouth and grasp/release patterns necessary for eating.
- Determining adaptive equipment needs and functional arm positioning to facilitate eating and other fine motor skills.

Speech-Language Pathologist/Specialist

Persons who have intellectual and developmental disabilities often have swallowing difficulties that worsen as they age. Recognizing subtle changes that put them at risk for aspiration is essential in keeping them safe. Speech-Language pathologists are often the specialists who assess speech, language development, and swallowing skills.

Speech-Language Therapist/Specialist duties include:

- Oral-Motor Function:
    - Assessing oral-motor function and swallowing status
    - Recommending, assisting and interpreting results of video fluoroscopy studies
    - Developing and managing exercises for swallowing
    - Recommending aspiration precautions, diet consistency and the degree of supervision required when eating. A physician’s order is needed to permanently change food textures
    - Assisting the individual and training caregivers in safe swallowing techniques

- Language and Communication
    - Evaluating language and communication skills
    - Assessing language comprehension and overall responsiveness
    - Developing and teaching exercises for speech and communication
    - Recommending, developing, implementing and maintaining alternative communication devices, such as visual communication systems

Components of a Basic Physical Assessment

Temperature, Pulse, Respiration, Blood Pressure

There are four major components to the basic physical assessment: temperature, pulse, respiration, and blood pressure. It is important that each component is taken occasionally when an individual is in his/her usual state of health. This data will assist in establishing a baseline. Otherwise, there is no data for comparison when the person is ill.

Temperature

Temperatures varying from 97°F to 99°F are considered normal and compatible with health.

Factors causing an increase in heat production and a rise in temperature are:

- Exercise- muscles working increase heat production and cause feelings of warmth throughout the body
- Shivering- another form of muscular activity
- Ingestion of food- increasing fuel supply increases amount of heat
- Strong emotions- excitement, anxiety, nervousness and similar emotions cause increased activity of secretory glands to increase heat production in body
- Increased temperatures of environment- high room temperature or hot bath may increase temperature
- Brief exposure to cold- stimulates body to increase heat production
- Very high external temperature- may upset balance of heat regulation and produce high body temperature, as in sunstroke
- Illness - an increased metabolic rate, used to fight infection, may cause an increase in body temperature

Factors causing a decreased heat production and a lower temperature are:

- Illness - muscular activity curtailed and less heat is produced
- Fasting - inadequate supply of food or fuel leads to decreased heat production
- Lowered vitality- in conditions of illness or injury in which body resistance is lowered, body functions are slowed and muscular activity diminishes so heat production is decreased
- Prolonged exposure to cold - reduces body temperatures
- Sleep – when the body is less active, less heat is produced and body temperature is lowered
- Depression - of the nervous system, mental depression, unconsciousness, use of narcotic drugs, all act to lessen activity and thus decrease heat production

Pulse

Pulse is the rhythmic expansion of an artery produced by increased volume of blood forced into it by contraction of left ventricle at each heartbeat.

Locations for taking pulse:

- Radial artery - thumb side of wrist (most common)
- Temporal artery - just above and to the outer side of eye orbit
- Carotid artery - on the neck on either side of the windpipe
- Femoral artery - in the groin
- *Do not use your thumb when taking pulses; your thumb has a pulse of its own.*

Factors causing variation in pulse rate:

- Age
- Gender (females faster than males)
- Physique - short and heavy people more rapid pulse than thin person
- Exercise - increased muscular activity causes temporary increase
- Food - slight increase for a few hours
- Posture - increased when standing, lowered when sitting or reclining
- Mental or emotional disturbance - temporarily increases pulse rate
- Increased body temperature - pulse usually elevated 10 beats per each degree of elevated temperature.
- Disease condition - heart, thyroid disturbance, infections are examples
- Drugs - stimulant drugs increase pulse rate; depressant drugs decrease pulse rate.
- Blood pressure - when blood pressure is low, pulse rate increases in attempt to increase flow of blood and therefore increase blood pressure; in high blood pressure, pulse is decreased.

Characteristics of pulse:

- Rate - number of detectable pulsations per minute
- Rhythm
  - *Regular* - beats are of uniform force and separated by equal intervals of time.
  - *Irregular or intermittent* - beat missed at regular or irregular intervals.
- Volume - full or large volume of blood in circulatory system is constant. Small, feeble, weak, thready, or flickering - volume decreased (example - hemorrhage).
- Pounding - pulse is large or full and rapid in rate.
- Volume of pulse is determined by size of pulse wave against fingers being used to take pulse.

Respiration

Respiration is the act of breathing. It is a continual process of drawing in and expelling air from lungs; the taking in of oxygen and elimination of carbon dioxide, water and other products of oxidation. Oxidation is the process of a substance combining with oxygen. Respiration is the exchange of gases between an organism and its environment. These are common characteristics of all living things. It is essential for chemical changes of metabolism which must take place if life is to be maintained.

Mechanics of Respiration:

- Each cell in body requires oxygen and food for maintenance of life and normal functioning.
- Chemical processes of metabolism take place within cells so food and oxygen must be supplied to all body cells. The universal waste product of metabolism is carbon dioxide, which must be eliminated not only from cells, but from the body itself.
- Exchange of gases in humans is a combined action of respiratory and circulatory systems.
- Usual ratio of respiration and pulse is approximately 1 to 4.

Factors causing variation in respiration:

- Age
- Gender (females slightly more rapid than males)
- Rate - increased respiratory rate causes breathing to be shallow. If respiration rate is decreased, depth of respiration may increase
- Exercise - muscular activity causes temporary increase in respiration
- Digestion - due to muscular and metabolic activity
- Disease conditions - depends on disease
- Drugs - depressant drugs, e.g., morphine and general anesthetics cause respiration to be slower and deeper. Caffeine and atropine stimulate respiration, thereby increasing respiration rate and shallow breathing
- Emotion - strong emotion, e.g. fear, causes increased rate
- Application of cold - stimulates nerve endings in skin and therefore breathing may be fuller and deeper
- Application of heat - may increase respiratory rate temporarily and cause shallow breathing
- Pain - severe pain causes increased respiratory rate and depth
- Toxins - acute infections stimulate respiratory center and cause increased respiratory rate and sometimes depth
- Fever - causes increase in pulse and respiratory rate
- Hemorrhage - decreased volume of blood with subsequent decrease in oxygen carrying capacity causes increased respiratory rate and depth
- Change in atmosphere pressure - in high altitudes, respiratory rate and depth increases as insufficient oxygen is available for external respiration. Normal amount of oxygen in the air is ample to meet needs of the body
- Shock - when blood pressure falls below life sustaining levels, it causes increased respiratory rate and depth

Conditions related to respiration:

- Apnea - a usually temporary period when breathing has ceased
- Dyspnea - difficult or painful breathing
- Cyanosis - blueness of skin and mucous membrane caused by lack of oxygen

Blood Pressure

Blood pressure is the force exerted by the blood against the walls of the blood vessels as it flows through them. It is produced by a combination of heart rate, amount of blood ejected from the heart each time it contracts, body blood volume and blood vessel size.

- Systolic pressure is the highest degree of pressure exerted by the blood against the artery walls as the left ventricle contracts and forces the blood from it into the aorta.
- Diastolic pressure is the lowest degree of pressure or the point of lessened pressure when the heart is in its resting period which is just before contraction of the left ventricle. It is produced by body blood volume and vessel size.
- Pulse pressure is the difference between systolic and diastolic pressure and represents volume output of the left ventricle. Pulse pressure indicates tone of the arterial walls and is valuable in diagnosis and treatment.
- Hypertension is a condition of abnormally high blood pressure.
- Hypotension is a condition of abnormally low blood pressure.
- Blood pressure readings may vary by time of day and body position. Blood pressure readings are taken for the purpose of comparison, therefore, they should be taken daily at the same time and with the individual in the same position each time (i.e. sitting).

Factors Causing Variation in Blood Pressure:

- Age- Blood pressure is lower in children than in adults; e.g., blood pressure of a young adult - 120/80; blood pressure of an older adult - 140/90.
- Gender- Men usually have higher blood pressure than women in the same age bracket.
- Body Build- Obese people usually have higher blood pressure.
- Exercise- Muscular exertion will increase blood pressure, although return to normal will occur shortly after exercise is discontinued.
- Pain- Severe pain may cause a temporary and marked increase in blood pressure.
- Emotions- Fear, worry, excitement and other emotions will cause blood pressure to rise sharply.
- Disease- Diseases affecting the circulatory system may cause an increase in blood pressure; e.g., arterio or athero sclerosis, kidney diseases and diseases caused by bacterial toxins; diseases that weaken the heart action may lower blood pressure.
- Hemorrhage- This causes lower blood pressure by decreasing volume of blood in the vessels.
- Intra Cranial Pressure-Increased pressure within the cranium usually produces an increased blood pressure.
- Shock- Lowered blood pressure is a symptom of shock and requires emergency treatment.
- Medication side effects

The Fatal Four

Aspiration, Dehydration, Constipation, Seizures

There are four major health issues that are more common in people with developmental disabilities than in the general population that can lead to severe sickness and even death. They are frequently referred to as the "fatal four" risks: aspiration, dehydration, constipation and epileptic seizures.

Aspiration, dehydration and constipation may be conditions that often go unrecognized because many of the symptoms are subtle and persons with disabilities may not be able to express their discomfort or give indications that they are not feeling well.

If a person has epileptic seizures, it is the suddenness and the unpredictability of this disorder that places the person most at risk. Injury, aspiration, drowning accidents and seizures that continue without stopping may cause hospitalizations and/or even death.

For all of the "fatal four" risks, alertness of the caregivers and careful monitoring can greatly minimize these hazards and ensure timely interventions should they occur.

Aspiration

Aspiration is defined as the inhalation of food, fluid, saliva, medication or other foreign material into the trachea and lungs. Any material can be aspirated on the way to the stomach or as stomach contents are refluxed back into the throat. In some cases, aspiration can lead to pneumonia and even death. The following information will help identify risk factors and interventions that may be unique to persons with intellectual and developmental disabilities.

Factors that place individuals at risk for aspiration:

- Being fed by others
- Inadequately trained caregivers assisting with eating/drinking
- Weak or absent coughing/gagging reflexes, commonly seen in persons who have cerebral palsy or muscular dystrophy
- Poor chewing or swallowing skills
- Gastroesophageal reflux disease (GERD), which can cause aspiration of stomach contents
- Food stuffing, rapid eating/drinking and pooling of food in the mouth
- Inappropriate fluid consistency and/or food textures
- Medication side effects that cause drowsiness and/or relaxed muscles may cause delayed swallowing and suppression of gag and cough reflexes
- Impaired mobility that may leave individuals unable to sit upright while eating
- Epileptic seizures that may occur during oral intake or failure to position a person on their side after a seizure, allowing oral secretions to enter the airway

Review the health history for aspiration risks:

- A diagnosis of risk for aspiration or past episodes of aspiration
- A diagnosis, such as cerebral palsy, muscular dystrophy, epilepsy
- GERD, dysphasia (difficulty in swallowing) or hiatal hernia
- History of aspiration pneumonia
- Needing to be fed by others
- History of choking, coughing, gagging while eating
- Needs modified food texture and fluid consistency
- Eating/swallowing evaluations and laboratory tests (barium swallow, pH study, etc.) that indicates dysphasia
    - Has unexplained weight loss or chronic dehydration
    - Takes medications that may decrease voluntary muscle coordination or cause drowsiness
- Has unsafe eating and drinking practices, such as eating/drinking rapidly and food stuffing
- Has chronic chest congestion, frequent pneumonia, moist respirations, persistent cough or chronically uses cough/asthma medications

Mealtime behaviors that may indicate aspiration:

- Eating slowly
- Fear or reluctance to eat
- Coughing or choking during meals
- Refusing food and/or fluids
- Food and fluid falling out the person’s mouth
- Eating in odd or unusual positions, such as throwing head back when swallowing
- Swallowing large amounts of food rapidly
- Refusing to eat except for “favorite caregiver”

Signs and symptoms that may indicate aspiration risks:

- Gagging/choking during meals
- Persistent coughing during or after meals
- Irregular breathing, turning blue, moist respirations, wheezing or rapid respirations
- Food or fluid falling out of the person’s mouth or drooling
- Intermittent fevers
- Chronic dehydration
- Unexplained weight loss
- Vomiting, regurgitation, rumination and/or odor of vomit or formula after meals

Aspiration interventions:

- Call 911 if the person stops breathing and start CPR
- Stop feeding/eating immediately (may restart meal if feeding/dining instructions, supervisor or health care professional give permission)

- Keep person in an upright position and encourage coughing
- If in doubt on what to do, call the health care professional or 911

Guidelines on how to prevent or minimize the risk of aspiration:

- Obtain a consultation by a swallowing specialist if symptoms occur
- Change diet consistency, texture or temperature (need a physician's order)
- Slow pace of eating and decrease size of bites
- Position to enhance swallowing during meal times
- Keep in an upright position after meals for 45 minutes or as ordered
- Elevate the head of the bed 30 to 45 degrees
- Avoid food/fluid 2-3 hours before bedtime
- Consider the use of medications to promote stomach emptying, reduce reflux and acidity
- Write an aspiration protocol and written instructions on how the person is to eat or be fed and provide caregiver training.
- The aspiration protocol should cover the following:
    - The assistance level needed
    - Correct positioning for all oral intake and tooth brushing
    - Eating/feeding equipment needed
    - Physical and verbal cueing needed
    - Location of meals (Some individuals may need to eat alone as they become distracted when eating with their peers)
    - Recognition of aspiration symptoms, what to do if noted and who to notify

Aspiration risks and feeding tubes:

Many individuals with intellectual and developmental disabilities that have swallowing difficulties have permanent feeding tubes surgically inserted. Having a feeding tube does not eliminate the risk of aspiration. Stomach contents can still enter the airway via regurgitation or oral secretions can be aspirated if the person has dysphagia. Occasionally anti reflux surgery will be performed to tighten the lower esophageal sphincter. Having this surgery will not conclusively eliminate the risk of aspiration, but should lessen the risk. Some standard aspiration precautions are:

- Administering tube feedings in an upright sitting position and keep upright for at least 45 minutes after.
- If the person must be fed in bed, keep the head of bed at a 45 degree angle while feeding and for 45 minutes to an hour after.
- Don't overfill the stomach.
- Nutrition given at room temperature is better tolerated.
- Don't feed too rapidly; feedings should be administered over at least 30 minutes or as ordered.

Constipation

Constipation is when an individual has difficulty passing stool; the stools are hard, dry and often look like marbles. The frequency of bowel movements varies greatly from person to person. Bowel movements are considered normal as long as the feces are soft, normal sized and are passed easily out of the bowel.

Factors that place individuals at risk for constipation:

- Neuromuscular degenerative disorders that impair the central nervous system's response for the need to eliminate
- Spinal cord injuries or birth defects that affect neural responses needed for elimination, such as spina bifida
- Individuals with muscle weakness who lack the strength and tone needed for adequate bowel function
- Diets that do not contain enough fiber and fluids
- Poor swallowing skills with aspiration risk making it difficult to eat and drink adequate amounts of fiber and fluid
- Inadequate or inconvenient access to the bathroom
- Immobility and poor body alignment that does not allow for optimum positioning for bowel elimination
- Poor toileting habits and routines or lack or privacy and time for toileting
- Medications that slow down gastric motility or draw too much fluid from the GI tract
- Hemorrhoids or other conditions that make bowel elimination painful
- History of frequent bowel stimulant use leading to decreased bowel reactivity
- Repression of the urge to defecate due to psychiatric issues

Review of health history for risk of constipation:

- Has a current or previous diagnosis of constipation.
- Has a routine order for bowel medications and/or treatments.
- Uses PRN bowel medications.
- Hospitalizations or outpatient treatments for constipation (bowel impaction, obstruction).
- Takes medications that affect the body's hydration status or have constipating side effects.
- Diet orders to increase dietary fiber (prunes, bran, psyllium, etc.) without adequate fluid intake.
- Individual has a constipation protocol.
- Caregiver's documentation indicates that the individual complains of stomach discomfort, strains with elimination, has abdominal distention, makes frequent trips to the bathroom or engages in rectal digging.
- Bowel record shows that the individual is passing hard feces or bowel movements more that 2 – 3 days apart.
- Recent decrease or stopping of routine bowel medications.

Signs and symptoms of constipation:

- Spending a lot of time on the toilet
- Straining and grunting while passing stool
- Refusing to eat or drink
- Hard, small, dry feces
- Hard, protruding abdomen (usually an emergency)
- Vomiting digested food that smells like feces (is an emergency)
- Bloating and complaints of stomach discomfort

Constipation Interventions:

- Dietitian consultation regarding the type of food, texture, fiber content and fluid requirements to enhance elimination
- Implement an individual constipation protocol and train caregivers:
    - How to identify constipation symptoms, what to do if they occur and who to notify
    - Fluid requirements
    - When to give PRN bowel medications and how to document the results
    - When to assist with bathroom use
    - How and where to document bowel movements
    - To report observations and/or data to the health care professional routinely and as needed

Guidelines on how to prevent or minimize constipation

- Encourage physical activity to increase muscle strength and tone.
- A positioning schedule for non-mobile individuals with time in an upright position
- Review of medications for side effects of constipation
- Establish toileting routines and schedule. For example: Drinking a warm beverage first thing in the morning.
- Teach the person to take slow, deep breaths to increase abdominal pressure during toileting.
- Teach the person to respond to the natural urge to defecate.
- Placing feet on a small step stool while sitting on toilet
- Providing enough time and privacy for toileting

Observations that should prompt concern:

- No bowel movement for more than three days
- Last two bowel movements were hard and/or small
- In the last three days, only small bowel movements recorded

Observations that should prompt a review by a health professional:

- Abdomen firm to touch and/or looks distended and bloated
- Complaints of stomach pain

- Vomiting without any fever or flu-like symptoms and/or vomiting material that smells like fecal material (call 911)
- Runny liquid stools after several days of passing small hard stools, small liquid stools or no bowel movements

Dehydration

Dehydration occurs when an individual does not drink enough fluids. Fluids are needed for temperature control, chemical balance and for cells to make energy and get rid of waste products. Dehydration occurs when the body loses more fluid than is replaced.

Factors that place individuals at risk for dehydration:

- Unable to access fluids without assistance
- Needing assistance with drinking
- Dysphagia with coughing and choking during meals
- Food, fluid and saliva falling out of a person's mouth
- Frequently refusing food and fluids
- Suppression of thirst mechanism that results in the inability to recognize thirst
- Unable to effectively communicate thirst to caregivers
- Medical conditions where fluid loss can potentially cause dehydration, such as kidney disease or diabetes
- Conditions where the individual loses body fluid, such as drooling, diarrhea, sweating and vomiting
- Taking medications that affect body fluid balance, such as diuretics
- Being in a hot environment without sufficient fluid intake

Review of health history for risk of dehydration:

- Physician has written a diagnosis of dehydration
- Physician has written an order for a minimum amount of fluid each day
- Has required intravenous fluids for dehydration either as an outpatient treatment or when in the hospital
- Takes a medication that affects body fluid balance, such as a diuretic
- Has a history of difficulty with drinking fluids, such as refusal or spillage
- Cannot independently access fluids or communicate thirst
- Has a protocol for dehydration
- Weight record reflects rapid weight loss
- History of frequent vomiting/diarrhea

Signs and symptoms that an individual may be dehydrated:

- Dry skin and poor skin elasticity
- Extreme thirst
- Dry sticky mucous
- Lethargy and decreased alertness
- Fever

- Increased heart rate and decreased blood pressure
- Decreased urination, dark colored urine and concentrated urine smell

Dehydration interventions
- Offer fluid intake if the individual is alert and able to drink safely
- If unable to take fluid safely, call health care professional for administration of intravenous fluids

Guidelines for dehydration prevention:
- Individuals should be encouraged to drink 8 – 10 glasses of fluid/day (64 – 84 ounces/day or 2000 – 2400 cc/day).
- Persons who weigh more must drink more; persons who weigh less need less.
- If a person is reluctant to drink fluids, offer foods high in fluid content, such as gelatin, watermelon, puddings, yogurt or ice cream.
- Persons who are very active, work hard, have a fever or perspire heavily need more fluids.
- Persons who have cardiac or kidney disease may need less fluid.
- A person with dysphagia needs a swallowing evaluation by a health care professional.
- Implement a dehydration protocol and provide caregiver training:
    - Have clear instructions regarding fluid requirements
    - List acceptable minimal amount of fluid intake/day
    - Consider the need for monitoring of intake and output
    - List signs and symptoms of dehydration, what to do if seen and who to notify

Seizure Disorder (Epilepsy)

Epilepsy is a disorder of the brain that is characterized by chaotic brain activity which often results in seizures. Individuals with intellectual and developmental disabilities are more likely to have epilepsy because of an underlying brain dysfunction. Head injuries, brain tumors and brain congenital abnormalities are some causes of epilepsy. The clinical expression of an epileptic seizure varies according to where it starts in the brain.

If there has been a seizure in the past 12 months or antiepileptic medications have been changed within the last 6 months, then water safety precautions (such as 1:1 continual observation in pool/tub, wearing a lifejacket, using shower only or no tub baths) must be considered.

Factors that place individuals at risk for epilepsy
- Prenatal and postnatal brain injury, such as trauma, anoxia, infection
- Congenital brain malformations
- Brain tumors, clots, hemorrhage, aneurysms
- Traumatic brain injuries
- Review of health history for risk of epilepsy
- Has a diagnosis of seizures, seizure disorder or epilepsy

- Has a history of a seizure(s) within the last five years
- Has an epilepsy protocol
- Takes antiepileptic medications for epilepsy or has had other treatments, such as a vagal nerve stimulator or ketogenic diet

Guidelines for seizure prevention:

- Give antiepileptic medications on time as prescribed (be sure a protocol for missed medication is in place)
- Promote good relationships with health care professionals/specialists
    - Provide accurate documentation and record keeping
    - Keep appointments and be on time

Immediate interventions when an individual has a seizure

- Stay with the person and guide gently away from or prevent access to dangerous areas
- Do not place anything in the person's mouth
- Move objects away from the person to prevent injury
- Only move the person if in an unsafe area such as a roadway or stairwell
- If in water, keep the person's head above the water
- Don't restrain the person's movements
- Cushion the person's head, arms and legs
- Keep track of how long the seizure lasts

After the seizure:

- Turn the individual on their side when relaxed
- Loosen clothing
- Check for injuries and treat appropriately
- Document the seizure on a seizure calendar or record
- Allow the person sufficient time to recover before returning to activities

Medication Principles

Approximately 35% to 50% of people with DD receive psychotropic medication. 65% of psychotropic medications prescribed are antipsychotics (Indiana Institute on Disability, 2011). The most common types of medications prescribed for people with intellectual and developmental disabilities include: antipsychotic, anti-anxiety, antidepressant, stimulant, and antiepileptic drugs.

Antipsychotic and Anti-anxiety Drugs
Antipsychotic and anti-anxiety drugs are medications most frequently prescribed for people with intellectual and developmental disabilities. They may be prescribed for conditions associated with aggressive, destructive and/or self-abusive behaviors. Antipsychotic drugs are generally strong or major tranquilizers. Anti-anxiety drugs refer generally to minor tranquilizers. Antipsychotic drugs are generally prescribed more often than anti-anxiety drugs.

Antidepressant Drugs
Antidepressant drugs are frequently prescribed for the treatment of depression in adults. This is especially true when the symptoms include psychomotor disabilities, sleep disorders, loss of appetite, weight loss, and constipation. They may be prescribed for conditions associated with behavioral problems such as hyperactivity and aggression.

Stimulant Medications
These are generally prescribed to treat minimal brain dysfunction, hyperactivity and attention deficit disorders. The intended outcome is to improve the attention span of the individual. They may be prescribed for individuals who demonstrate short attention spans, aggression toward others, impulsiveness, and restlessness.

Antiepileptic Drugs
Antiepileptic drugs are used in the treatment of seizure disorders. People with intellectual and developmental disabilities have an increased incidence of epilepsy. The percentage of individuals with intellectual and developmental disabilities who also have epilepsy increases with the severity of disability. Antiepileptic drugs can be successful in the treatment of epilepsy; however, only 50% of people can achieve complete seizure control through use of these medications. The nature and unpredictability of the side effects associated with the drugs also require that they be closely monitored.

Taking any medication poses some potential risk. These risks are referred to as *side effects*. Two major classifications of drugs are prescription and non-prescription. When taken with a prescribed medication, non-prescription drugs may alter the effect of the prescribed medication. For this reason, it is critical that you consult the physician or pharmacist when using non-prescription drugs if a prescription drug is already being used.

Medication Rules to Remember

1. Medications may not always work as intended.
2. Medications may produce an effect that is different from the effect that was desired.
3. Medications may produce no effect.
4. Medications may produce an opposite effect than the desired effect.
5. Medications may make a problem worse. These are called adverse effects (life threatening) or side effects (undesirable).
6. Some medications can have good or bad reactions with other medications already being taken.
7. Many medications taken for mood and behavior may take time to work (such as antidepressants).
8. Be patient when new medications are started. They may take 3-4 weeks to work and side effects may begin at once.
9. Give medications on time and as prescribed.
10. If someone has kidney or liver problems, medications may make these conditions worse.

For any person taking medications, monitor and report the following:

- Changes in the color of the stool
- Changes in the color of the white part of the eye
- Changes in the color of tissue under the tongue
- Stomach pain or increase in size of the stomach
- Weight gain or swelling (edema)
- Cloudy urine with increased odor
- Blood in the urine or stool
- Increased, frequent , or decreased urine output

Self-Medication

Some individuals have been taught to take their own medication. Others may be capable of learning this valuable skill. The ability to handle one's own medication allows an individual to have more choices of living arrangements.

An assessment should be made of each individual's ability to self medicate. The assessment by the nurse, the IDT and the physician will determine whether the individual is currently independent and whether or not he/she would benefit from training. A physician's order is required, as well as the approval of the person’s support team.

If the individual is assessed to be not fully competent in self medicating, a training program must be implemented. Almost any individual could benefit from some level of training, something as simple as identifying their own medication to something as complicated as making their doctor's appointments and ordering and picking up their own prescriptions.

Refusal of Medications- The Right to Refuse

People always have the right to refuse to take medications. It is your responsibility to work with and support individuals in taking medication; however, if someone refuses to take a medication, you should always try to determine the reason why the person is refusing. Common reasons for refusing medication:

- Unpleasant side effects such as drowsiness
- Unpleasant taste
- Doesn’t understand what the medication is for
- In denial that the medication is needed

Agency specific protocols for handling refusal of medication should be reviewed.

It is NEVER okay to crush or hide the medication in food or drinks to get a person to take his/her medication. The only time it is permissible to crush or alter any medication is if the medical professional gives permission for you to do so. If you think crushing the medication, or mixing it with food will make it easier for the individual to swallow, then you must first discuss this with the physician.

Unpleasant Taste

Please be aware that many medications cannot be crushed. If you crush some pills that are designed to be released slowly, you will get all of the medication at once. Other formulations also require that you don't crush or split. Some medications shouldn't be taken with milk. Others shouldn't be taken with juice.

Please talk to the pharmacist before trying any of the following:

- Taking a taste of honey after swallowing the pill
- Using ice chips to suck on before taking the pill
- Filling your mouth with a beverage before taking the pill

Drowsiness

If the individual refuses to take their medication because of drowsiness, you should discuss it with the prescribing physician. The doctor may suggest that the medication be taken at a different time of day (such as before bedtime), or an alternative medication may be available which does not cause drowsiness.

Lack of Understanding

If you are providing assistance to someone with intellectual and developmental disabilities and they refuse to take a medication, it may be because they do not understand what the medication is for. Sometimes simply talking with the person about the reason for the medication can help them be more willing to take it.

Denial of Need for Medication

Sometimes people may deny that they even need the medication. You should explain the need to them in language they understand, but don't argue with the person. Sometimes a simple statement from the physician to the individual to remind them to take the medication every day can help.

Even when you are armed with the best strategies, people you help support may still refuse to take medications. If you are assisting someone with intellectual and developmental disabilities who refuses his/her medication, you should respect the individual's right to choose not to take it. However, be sure to document the time, date, and medication missed in the person's clinical record and MAR and bring it to the attention of the medical health professional. Complete a Medication Error report and be sure to follow your agency's policy and procedure.

Medication Side Effects

Tardive Dyskinesia
Tardive dyskinesia (TD) is generally defined as a variable combination of abnormal voluntary movements associated with the long term use of older generation antipsychotic or 'neuroleptic' medication such as Mellaril and Haldol. These medications are used to treat such things as schizophrenia, bipolar disorder and Tourette's Syndrome. Medications such as Risperdal (Risperidone) and Abilify (Aripiprazole) are also approved to treat irritability in a person with Autism. The abnormal movements of TD may affect the face, eyes, mouth, tongue, trunk and upper and lower limbs. Some movements include grimaces, bursts of blinking, thrusting, twisting or jerking movements of the arms, hands, feet, or toes. The muscles of respiration and speech can be impaired by TD too. In the worst cases, a person with TD will thrash about continually.

TD severity may be related to greater antipsychotic medication dose or greater cumulative dose over time and organic factors. Elderly patients are thought to be at greater risk for severe TD than younger people. Also, gradual antipsychotic reductions may be associated with less severe forms of TD than abrupt reductions.

Unfortunately at this time, there is no cure for TD. Most doctors treat TD by discontinuing or lowering the dosage of the medication believed to be causing the TD. Some drugs, such as Tetrabenzine, Miraplex, and Clozapine, show promise in treating the condition.

Some of the older generation of neuroleptics which may cause TD include (Generic name of medication is listed first)

- Chlorpromazine (Thorazine)
- Fluphenazine (Prolixin)
- Halperidol (Haldol)
- Thioridazine (Mellaril)

Newer generation neuroleptics include:

- aripipizol (Abilify)
- olanzapine (Zyprexa)
- quetiapine (Seroquel)
- resperidone (Risperdal)
- ziprasidone (Geodon)

The newer atypical antipsychotics are safer than the older generation when it comes to TD.

Medications used for treatment of digestive conditions include:

- metroclopramide (Reglan) used to treat GERD/heartburn
- prochlorperazine (Compazine) used to treat frequent nausea and vomiting

There are a number of neurological, systemic and behavioral conditions which may be confused with TD because of abnormal movements that may be associated. Some conditions which can affect a person’s movements and may be detected when doing a TD assessment are:

- Age
- Cerebral Palsy
- Contact lenses
- Down Syndrome
- Drug Intoxication
- Heavy Metals
- Huntington ’s Chorea
- Hyperthyroidism
- Parkinson’s Disease
- Tourette’s Syndrome

TD Assessment Scales

First, it is important to understand that assessment instruments, or TD scales, are not diagnostic instruments. They give an idea of what movements are occurring in a “snap shot” of time; however, they are not diagnostic tests and do not explain what may be causing the movements observed.

Two of the most widely used scales are:

- Dyskinesia Identification System: Condensed User Scale (DISCUS)
- Abnormal Involuntary Movement Scales (AIMS)

Neuroleptic Malignant Syndrome

Neuroleptic malignant syndrome is a life-threatening, neurological disorder most often caused by an adverse reaction to neuroleptic or antipsychotic drugs. Symptoms include high fever, sweating, unstable blood pressure, stupor, muscular rigidity, and autonomic dysfunction. In most cases, the disorder develops within the first 2 weeks of treatment with the drug; however, the disorder may develop any time during the therapy period. The syndrome can also occur in people taking medications for Parkinson’s known as dopaminergics if those drugs are discontinued abruptly.

If this condition occurs, generally, intensive care is needed. The neuroleptic or antipsychotic drug is discontinued, and the fever is treated aggressively. A muscle relaxant may be prescribed. Dopaminergic drugs, such as a dopamine agonist, have been reported to be useful.

Early identification of and treatment for individuals with neuroleptic malignant syndrome improves the outcome. If clinically indicated, a low potency neuroleptic can be reintroduced very slowly when the individual recovers, although there is a risk that the syndrome might recur. Another alternative is to substitute another class of drugs for the neuroleptic. Anesthesia may be a risk to individuals who have experienced neuroleptic malignant syndrome.

Nutrition

Nutrition is an important factor affecting health. A balanced diet of healthy foods, along with healthy exercise, is the best way to maintain good health.

Obesity is epidemic in America. 2/3 of American adults and 1/3 of American children are obese. Contributing factors to this condition include over-consumption of foods with low nutritional value, portion sizes that are too large, eating an unbalanced diet and not enough physical activity.

Dietary guidelines, developed by the federal government and updated in 2010, are easy to understand with the My Plate model. Even so, one size doesn't fit all.

Special dietary needs or restrictions must be considered. Factors influencing special dietary considerations relevant to people with intellectual and developmental disabilities include:

- Obesity
- Diabetes
- Choking/swallowing dysfunction
- Pica
- Food intolerance/allergies
- Need for special nutrients

In order to complete the checklist below, it is necessary to know the person's dietary needs and restrictions, observe food supplies in the home, observe the person at mealtimes and speak to the cooking staff about requirements.

Considerations for proper nutrition:

€ Meals are planned based on individual's nutritional needs and preferences.

€ Meals are prepared according to plan.

€ Where necessary, a monitoring mechanism is in place for determining if the individual is consuming food according to the plan.

€ Nutritional snacks are available.

€ The diet is varied.

€ Food is prepared and stored in sanitary manner.

€ Adaptive devices are provided to maximize independence in eating and preparing food.

€ The meal planner is aware of drug/food interactions and other dietary restrictions/requirements.

€ The individual is being provided diet and preparation education.

€ Food choices and preferences are valued.

€ Food substitutions are available.

Support Strategies for Unexplained Weight Loss

Determine if the service plan continues to be appropriate and revise the plan if necessary. Determine if the person has experienced an emotional trauma, loss or any other significant life change.

You may want to make observations during meals and determine if services are being provided as described in the service plan (e.g., staff providing assistance and/or encouragement during dining; serving food as planned with attention to portion sizes, preferences, nutritional supplements, and/or between-meal snacks). Observe at least two meals. For each person being observed, identify any special needs and the interventions planned to meet their needs.

For example:

- Individual’s eyeglasses, dentures, and/or hearing aids are in place
- Proper positioning in chair, wheelchair, geri-chair, etc., at an appropriate distance from the table (tray table and bed at appropriate height and position)
- Assistive devices/utensils identified in service plans provided and used as planned.

Observe the food service for:

- Appropriateness of dishes and flatware for each resident, as applicable
- Delivery to residents in a timely fashion
- If a substitute was needed or requested, did it arrive timely?
- Were diet orders, portion sizes, preferences, and condiment requests being honored?

Choking

Factors that Increase the Risk of Choking

Individuals with intellectual and developmental disabilities may have a number of factors that increase the risk of choking, including but not limited to:

- Neurological and muscular disorders such as cerebral palsy and seizure disorders
- Dysphagia (difficulty swallowing)
- Side effects from medications
- Gastroesphogeal reflux disease (GERD)
- Difficulty swallowing
- Few or no teeth
- Dentures
    - Can make it difficult to sense whether food is fully chewed before it is swallowed
    - If dentures fit poorly or hurt, individuals might not want to chew their food or may not wear them and be unable to chew their food
- Placing too much food or medication in one's mouth
- Not chewing food well enough prior to swallowing
- Eating or drinking too fast
- Inattention while eating
    - Talking, laughing, walking, running or playing
    - Distracted by other persons or activities
- Poor posture while eating
- Swallowing non-edible objects (Pica)
- Food stealing - resulting in eating quickly
- Incorrect diet texture - liquids or food items not prepared correctly
- Eating something with two or more diet textures, especially anything with a thin liquid and a solid component such as cereal and milk

Common Foods Identified as "High Risk" for Choking

- Hotdogs
- Chicken on the bone
- Grapes
- Peanut butter
- Peanut butter sandwiches on soft bread
- Thick chewy bread, e.g. white bread, bagels, pizza, etc.
- Marshmallows
- Dry, crumbly foods such as cornbread or rice served without butter, jelly, sauce, etc.
- Dry meats such as ground beef served without sauce, gravy
- Whole, raw vegetables served in large bite-sized pieces
- Whole hard fruits like apples or pears

- Candy with large nuts
- Hard nuts
- Hard candy

Awareness is the First Step of Prevention

Because of the risk factors associated with choking, it is critical to provide adequate supervision of persons served, and be trained and familiar with individuals' needs:

- Prescribed diets
- Meal time or Pica precautions
- History of previous choking incidents or difficulty swallowing
- Properly assisted eating techniques
- Positioning during and after meal time
- Required supervision during meals

Important Safety Tip

It is common for people who are choking to either leave the table or move around very quickly. Be alert for those who leave without warning or who get up, move quickly and appear to be agitated.

Emergency Response to Choking

a. Immediately call 911. If another person is present, instruct them to call 911.
b. Follow your agency's training for responding to a choking victim.
c. Immediately provide repeated abdominal thrusts, known to some as the Heimlich maneuver, until the object causing the choking is dislodged and the individual can cough forcefully, speak or breathe, or until the individual becomes unconscious.
d. If the individual is unconscious, remove any visible obstructions from the mouth and begin administering CPR. Check periodically to see if the obstruction becomes dislodged.

Indicators of PARTIAL Airway Obstruction

- Able to speak, cry, and respond to you
- Breathing is noisy, labored, or gasping. Some air will come from the mouth
- Coughing, or making "crowing" noises
- Very agitated or anxious
- Skin becomes paler, may have bluish tint

Emergency Response to Partial Obstruction of Airway

a. Reassure the individual.
b. Encourage the individual to cough.
c. Avoid giving the individual anything to eat or drink.
d. Keep monitoring the situation.
e. Call an ambulance if the obstruction is not removed, or you can hear wheezing or noisy breathing.
f. If the obstruction is cleared, always have medical/nursing personnel determine if there is a need for additional clinical follow up.

Special Diets

The act of swallowing involves chewing food and moving it into the back of the mouth to transport it down the esophagus, the tube that moves food to the stomach. Difficulty with swallowing is the feeling that food or liquid is stuck in the throat or at any point before the food enters the stomach. This problem is also called dysphagia. Any symptoms of difficulty swallowing must be investigated. After a visit to the individual’s healthcare provider, a swallow study may be needed.

Swallowing is a complex act. Many nerves work in a fine balance to control how the muscles of the mouth, throat, and esophagus work together. Much of swallowing occurs without you being aware of what you are doing. The people that we help support may have a variety of disorders which make swallowing difficult.

A brain or nerve disorder can alter the fine balance in the muscles of the mouth and throat. An individual may first notice having problems only with certain types of foods or liquids. Difficulty eating very hot or cold foods, dry crackers or bread, meat, or chicken may be an early sign of swallowing problems.

If a special diet is ordered for someone that you help support, it is critical that the diet is followed at all times. **All** staff that provide support to the individual who is on a special diet must be trained in how to prepare the diet and in any mealtime assistance that an individual requires. This training should be thoroughly documented.

The table of food items for each type of diet is meant for example only. You should follow diet that is prescribed for the individual by the health care provider.

Chopped Texture

Purpose: This diet is for persons who have difficulty chewing some regular foods or have difficulty cutting up foods.

Diet Principles: Some foods are modified by dicing, chopping or cutting into bite-sized pieces as tolerated. Most meats are cubed and raw vegetables and hard fruits are finely diced. This diet texture can be applied to any portion size or therapeutic diet.

FOODS FOR THE DAY	EXAMPLES OF FOODS ALLOWED	EXAMPLES OF FOODS TO AVOID
MILK & MILK PRODUCTS	Milk, cottage cheese, sliced cheese	None
MEAT OR SUBSTITUTE	Cubed meat and poultry, whole fish, tender sliced lunchmeat and cheese, eggs, cooked dried beans and peas	All others
BREADS, CEREALS, PASTA & RICE	Whole grain, enriched bread, cereals, crackers, pasta, or rice	None
VEGETABLES	Cubed cooked vegetables, shredded lettuce, vegetable juice, finely diced raw carrots and celery. White or sweet potato	Whole raw vegetable salads, whole raw carrots and celery
FRUITS	May be fresh, canned, or frozen, served whole (except apples), diced, or as juice. Soft fresh fruit as tolerated	Whole fresh apples, Whole hard fresh fruit
FATS	Margarine, butter, salad oil, mayonnaise	None
DISCRETIONARY CALORIES	Puddings, ice cream, sherbet, cakes, cookies, gelatin, pastries, pie, sugar, jelly, salt, herbs and spices, flavorings, pepper	None

Ground Texture

Purpose: This diet is for persons who have difficulty chewing and/or swallowing. It is intended to minimize the need for chewing and to ease swallowing.

Diet Principles: Foods are finely minced or ground, and moistened. Foods that are fork-mashable are included. This diet texture can be applied to any portion size or therapeutic diet.

FOODS FOR THE DAY	**EXAMPLES OF FOOD ALLOWED**	**EXAMPLES OF FOODS TO AVOID**
MILK & MILK PRODUCTS	Yogurt, cottage cheese, custard, cheese spread (ground)	String cheese or other cheese larger than diced
MEAT OR SUBSTITUTE	Moistened ground meats, ground dried beans, meat salads made with ground meat and vegetables, scrambled eggs, soft tofu	Unmoistened meats, whole hamburger patty, cold cuts, whole hard cooked egg
BREADS, CEREALS, PASTA, & RICE	Soft, moist bread products such as moistened breadcrumbs or bread pudding, cooked cereals (oatmeal, farina, malt-o-meal), moistened rice and small chopped pasta	Bread with: seeds, nuts, dry fruits, unsoaked crackers, gold fish crackers, teddy grahams, dry cereal, coarse whole grain cereals not softened by soaking
VEGETABLES	Minced or ground tomatoes, peas, beets, lima beans, creamed or pureed corn, kidney beans, spinach, gelled vegetable salads, mashed potatoes, ground tater tots, minced potato salad, tender steamed potatoes that can be mashed with a fork	Raw crunchy vegetables without sauce or dressing, potato chips, whole French fries
FRUITS	Ground or minced baked apples, ripe banana, peaches, crushed pineapple, canned/cooked fruit, applesauce, pureed raisins, fruit cocktail, blueberries, strawberries, pineapple sauce and pureed bananas can be used if crushed pineapple and minced bananas are not tolerated	Raw and crunchy fruit, fruit roll-ups, dried fruit, coconut
FATS	Margarine, butter, salad oil, mayonnaise	None
DISCRETIONARY CALORIES	Moistened soft cookies, cubed cake	Seeds, unmoistened cookies, plain peanut butter

Pureed Texture

Purpose: This diet is for persons who have chewing or swallowing problems and may not safely handle a ground texture.

Diet Principles: Foods are pureed to smooth consistency unless already in a comparatively smooth form such as mashed potatoes. This texture can be applied to any diet portion size or therapeutic diet.

FOODS FOR THE DAY	EXAMPLES OF FOOD ALLOWED	EXAMPLES OF FOODS TO AVOID
MILK & MILK PRODUCTS	Yogurt, pureed cottage cheese, custard, ice cream	Hard and semi-hard cheeses used alone
MEAT OR SUBSTITUTE	Pureed meat, poultry, fish, eggs, cooked dried beans, soft tofu	All others
BREADS, CEREAL, PASTA, & RICE	Moistened bread crumbs or pureed baked bread pudding, cooked cereals (pureed oatmeal, farina, malt-o-meal), moistened pureed rice or rice cereal, pureed pasta	All others, dry cereal, coarse whole grain cereals not softened by soaking
VEGETABLES	Pureed: tomatoes, peas, beets, lima beans, pureed creamed corn, kidney beans, spinach, pureed gelled vegetable salads, mashed potatoes, pureed tater tots, and pureed potato salads	Whole creamed corn, all other potato products
FRUITS	Pureed: baked apples, banana, peaches, pineapple sauce, canned/cooked fruit, raisins, fruit cocktail, blueberries, strawberries and applesauce	Raw and crunchy fruit, fruit roll-ups, dried fruit, coconut
FATS	Margarine, butter, salad oil, mayonnaise	None
DISCRETIONARY CALORIES	Pureed soft cookies or cake, ice cream, pudding	Seeds, unmoistened cookies, peanut butter (by itself)

Thickened Liquids

Thickened liquids are prescribed for some individuals with swallowing problems. Thickeners slow the flow of liquids and make them easier to swallow. The degree of thickness that the individual may need to swallow safely is prescribed by the health professional after a swallow study is performed.

Nectar Thick Liquids: This is slightly thickened.

- Fork test: Liquid coats the fork and quickly sinks through the prongs.
- Spoon test: Liquid leaves spoon in a fine "ribbon" or "trail" when poured or stirred, similar to heavy syrup found in canned fruit, or to maple syrup.

Honey Thick Liquids: This is thicker than nectar, closer to honey.

- Fork test: Liquid coats the fork and flows slowly through the prongs.
- Spoon test: Liquid flows slowly from spoon but still pours, somewhat like a milkshake.

Pudding Thick Liquids: This is the thickest. It does not pour, but drops from the spoon.

- Fork test: Liquid remains on fork.
- Spoon test: Liquid does not pour from spoon. The spoon stands up in product and liquid requires a spoon for eating.

Preparation

Follow manufacturer's recommendations EXACTLY for measurements of both the commercial thickener and the liquid. Follow recommendations for waiting time for the thickener to work. USE NO MORE THICKENER THAN NECESSARY to avoid excess calories and over-thickening.

Pica

Pica presents a serious risk to a person's health and should not be disregarded or taken lightly. It can result in serious illness, surgery and even death. It is important to understand the condition and its specific manifestation in an individual. A well developed safety plan will give caregivers the information that they need to assist individuals to live safe, happy and healthy lives.

Pica is defined as the compulsive eating of non-food items. There are many theories about the cause of pica; however, within the field of intellectual and developmental disabilities the cause often remains unknown. Some *possible* causes of pica behavior include:

- Medical problems
- Psychiatric illnesses
- Behavioral functions

Individuals who have pica may seek out a wide variety of items to ingest. The behavior is very individualized. Some may seek out specific items to ingest while others may ingest any small item in their environment. Therefore a plan/protocol for safety must be developed specifically for the person, their pica behavior and health risks.

Prader-Willi, a syndrome characterized by chronic feelings of insatiable hunger, can lead to excessive eating and life-threatening obesity. Like those with Pica, individuals with Prader-Willi may require consistent and unique care to avoid a health crisis.

At times it may be necessary to restrict a person's access to food. When considering such restrictions, proper protocol must be followed.

Discuss your agency's Human Rights Committee and related policies and procedures.

Risks associated with putting non-food items into the mouth and/or swallowing:

Bowel blockage – items that are swallowed may clump or stick together and eventually block the bowel. These items may include:

- String, thread or fuzz
- Paper
- Disposable gloves (latex, plastic)

Ulceration and perforation

Any object that stays in contact with one spot in the bowel can cause ulceration and eventually perforation. Coins are particularly dangerous. Any sharp object, such as a safety pin or screw can puncture the esophagus, stomach or intestines.

Poisoning/Toxicity/Parasitic Infection

- Furniture polish – damages the lungs
- Cleaning solvent
- Antifreeze – damages the kidneys
- Batteries
- Paint chips from lead based paints
- Cigarettes and butts
- Dirt from areas frequented by pets/animals
- Pet feces

Choking/Aspiration

- Non-food items large enough to block the airway

Dental and Mouth Injuries

- Items too hard to chew (rocks, buttons, etc.)

Nutritional Deprivation

- Eating enough non-food items to displace legitimate caloric intake

Pica Prevention

Techniques for coping with Pica behaviors fall into these categories:

- Sweeping
- Adapting
- Avoiding
- Interfering

Sweeping

Sweeping is a simple way to identify potential hazards in the area.
A sweep has five steps:

- *Stop* – Keep the person from entering a new area before the sweep is done.
- *Look* - Spot any possible hazards in the area.
- *Investigate* – Decide on the risk from each of the possible hazards.
- *Document* – Keep track of the hazards that are found.
- *Eliminate* – Get rid of any likely hazards when feasible.

Adapting

Adapting the person’s daily tasks is usually required. An adaptation task has these steps:

- *Assess* – Look at each new task.

- *Identify* – Spot the likely hazards for the person in each task.
- *Modify* – Adapt the new task to remove the item.

Avoiding

Avoiding some places at the times when Pica is most likely to happen is a good way to prevent it. Avoiding pica behavior has these steps:

- *Locate* the places the behavior is most likely to happen.
- *Identify* – Spot the likely hazards for the person in each location.
- *Plan* – Schedule to avoid the places at times that the Pica behavior could happen.

Interfering

Interfering with Pica behavior by giving the person other things to do can help to prevent the behavior.

- *Find* – Design tasks that get in the way of the behavior.
- *Be* sure that the tasks are safe for the person to do.
- *Assure* that the task is one the person can do.

Other tips to help prevent Pica from occurring include:

- Limit access to environments that are not rigorously monitored for small indigestible items.
- Ensure close supervision of the individual and that all caregivers understand the individual's risk of Pica.
- Develop a protocol specific to the individual and their support needs; provide caregiver training in all locations where the person spends time.
- Consider the need for routine surveillance (Pica sweeps) of the areas frequented by the individual to find and remove targeted Pica items.
- Avoid clothing with buttons/bows that can be pulled off.
- Avoid toys/gifts with small pieces that can be chewed or broken off and swallowed.

Discuss the following:

Is anyone here currently serving or has anyone previously served an individual with Pica?

What measures have you used to interfere with the disorder? Have you had any success?

How does Pica differ from Prader-Willi?

<u>Protocol/Safety Plan</u>

A protocol/safety plan should be developed with input from the people who know the individual and their environment best.

Five Steps of a Safety Plan include:

1. A list of the things that the person might either swallow or attempt to swallow
2. A system for keeping track of both ATTEMPTED, as well as, COMPLETED ingestion

3. Strategies for preventing any attempt
4. A plan for training staff
5. Criteria for revising the safety plan

The plan should also give guidance for:

- When to call 911
- When to call poison control (the phone number of poison control should be posted by every phone)
- List times/locations where pursuit of items is most likely, if known
- Steps in prevention, such as Pica sweeps, no buttons on shirt, etc.
- Signs and symptoms that the individual may display if a non-food item is swallowed

Verbal encouragement can be used to coerce an individual into spitting out non-food items. Staff should be trained not to put their hands, fingers, etc. into an individual's mouth in an attempt to remove objects. If a non-food item is suspected of having been ingested, the individual must be monitored for symptoms of obstruction, infection, poisoning or other adverse effect.

The following symptoms may indicate a need to notify the physician:

- Refusal of food or fluids or decreased intake
- Lack of bowel movements or small watery stools
- Abdominal pain and discomfort
- Vomiting
- Fever
- Hard or protruding abdomen
- Walking stooped or bent over as if in pain (if not usual for the individual)
- Complaining of not feeling well or not wanting to get out of bed, go to work or participate in favorite activities

If an individual displays Pica behavior for the first time, it is essential to ensure that the physician is informed of the following facts:

- A clear description of the behavior, clarifying that it is new to the person
- Any data collected on frequency
- Specific items that the person is seeking out

Aging

Older people can expect some decline in their five senses. While the sense of smell, taste and touch all change with age, often the most noticeable changes affect our vision and hearing. As senses change, older people may find it more difficult to socialize and participate in activities. Changes to our senses may also increase the need for assistance with personal care.

Hearing

Starting around age 30, we begin to experience hearing loss. By age 40 or 50, it can be hard for many people to distinguish between sounds that are coming from nearby or farther away. Higher tones such as the voices of women and children can be more difficult to hear as we age. These higher tones also help us to *understand* speech. Frequently, people with a hearing loss in the higher tones complain that they can hear speech, but are unable to understand what is being said.

Older people may find it hard to engage in or follow a conversation. It can be challenging to talk on the telephone, hear music or hear the television. People with hearing loss often use hearing aids or hearing devices, sometimes called “Assistive Listening Devices”. Others may choose to avoid social situations where their impairment may be noticeable or they may feel conspicuous or uncomfortable.

Possible signs of hearing loss:

- The radio or TV volume is on very loud.
- The individual may ask you to repeat things.
- You notice the person watching your mouth very closely.
- If you turn your back to the person, he/she does not hear or understand you.
- The individual talks unusually loud, yet doesn't realize it.
- The individual doesn't hear the door bell or a knock at the door.

Support Strategies:

- Schedule regular exams with an Audiologist to check for wax, disease and gradual hearing loss
- Obtain amplification (hearing aid or assistive listening device) if indicated
- Speak slower
- Reduce background noise
- When speaking, face the person with light on your face (not behind you)

To participate in a hearing loss simulation, listen to the computer generated samples at http://www.cdc.gov/niosh/mining/content/hlsoundslike.html

Smell

Aging may gradually reduce the ability to detect and identify odors. Other factors which affect smell include smoking and medications.

Older people may be less aware of body odor or excessive use of perfume, and may lose their natural ability to detect spoiled food or smoke. Regularly replace smoke detector batteries; a good rule of thumb is to change the batteries when the time changes. If a person has body odor, it is important to respectfully bring it to his or her attention to help maintain their dignity. A person may not notice odors or detect unsafe smells. Offer support and kind words to help avoid potentially embarrassing or dangerous situations.
Watch carefully what the person eats.

- Be aware of exposure to chemicals such as ammonia, bleach, smoke or gas, which may cause harm. Remove the individual from such situations.
- Eating spoiled food or not reacting to bad smells might indicate that an individual is losing their sense of smell.

Support Strategies:

- Be sure to use smoke detectors
- Use care if using propane stoves or water heaters
- Discard food after recommended time, check for spoilage
- Assist with awareness of body odor or over-use of fragrances

Taste

The intensity of taste and the ability to identify different tastes diminishes as we age. Older people tend to maintain the ability to detect sweet taste, but have more difficulty detecting sour, salty and bitter tastes. Other factors that affect taste include dentures, medications and smoking.

Concern – If older people find eating to be less enjoyable or satisfying, they may eat less often or eat only those foods with a distinctive or strong flavor. It is important for people of all ages to eat a healthy and balanced diet, not just the foods that taste good.

Touch /Sensitivity

With age, the sense of touch often declines due to skin changes and reduced circulation. Skin is less sensitive to temperatures such as hot and cold water. Small motor skills such as opening a jar or handling silverware may also become more challenging. People with arthritis, diabetes or vascular disease may face additional challenges and limitations.

Concern – Many older people may not be aware of their diminished sense of touch and as a result could unintentionally injure themselves. People leading a more inactive or sedentary lifestyle are often less sensitive and may not notice potential dangers. No reaction (or a slow one) to a change in temperature or pain may be a sign that a person is losing his sense of touch. If a person loses their sense of touch, he may be at risk of hypothermia or hyperthermia, heat stroke, burns, or frostbite. Watch the person closely as he may not react to water temperatures that may cause burns.

Protecting the skin:

- Minimize use of soap and rinse well
- Dry well and use moisturizers
- Reposition frequently if mobility is limited
- Check skin frequently for sores, dryness or other abnormalities
- Label hot and cold water and monitor water temperatures
- Use sun protection. The individual may stay longer in the sun than usual and cause sunburn. Be sure people wear 15+ sunblock when outside.

Vision

Aging may cause noticeable vision changes. The pupil of the eye becomes less responsive to changes in lighting making it difficult to see in the dark. The lens of the eye gradually thickens and yellows. There is a loss in visual acuity, which is the ability to notice detail. An older adult may openly share concerns about his/her vision. But sometimes the change occurs so gradually that the individual adapts and is not aware of the changes. Of the many eye diseases that affect older people, the most common are cataracts, diabetic retinopathy, glaucoma and macular degeneration.

- Cataracts are a gradual clouding of the lens of the eye, making images less clear and sharp.
- Diabetic retinopathy is caused by a lack of circulation to the retina where the arteries in the retina become weakened and leak, forming small spots that cloud a person's vision.
- Glaucoma is a buildup of pressure inside the eye that ultimately can destroy the optic nerve and lead to blindness.
- Macular degeneration causes deterioration of the retina, responsible for focusing central vision in the eye. It becomes difficult to read and recognize detail, and over time can cause blindness.

Concern -It can become difficult for older people to see in dimly lit places such as a restaurant or theatre. Night driving and driving in rainy conditions can be dangerous due to an inability to see road signs, judge distance or recover from the sudden glare of oncoming traffic. As we age, many people will rely on reading glasses, bifocals or trifocals to help maintain their eyesight. Medical treatment or surgery may be an option for many conditions.

To gain an understanding of how different eye diseases can affect vision, visit the following website: http://www.nei.nih.gov/health/examples/index.asp

Symptoms of the problem:

- Rubbing eyes
- Squinting
- Shutting or covering one eye

- Tilting or thrusting head forward or to one side
- Redness of eye or area around eyes

Changes in Function:

- Stumbling
- Hesitancy on a step or curb
- Holding objects/books closer to eyes
- Sitting closer to TV

Some clues to look for:

- Wearing spotted, soiled or mismatched clothing
- Using non-visual methods such as searching with their hands for an object, or searching for the edge of a chair to walk around it
- Needing more lighting for activities
- Falling or bumping into furniture or doorways
- Not aware of a decline in cleanliness of living area

Support Strategies:

- Use bright contrasting colors around doors and steps.
- Avoid highly polished surfaces. This will allow for good light, yet limit the glare.
- Use bright light. This will help the person know the difference between detail and colors.
- Limit the time of "close work" (for example, knitting or reading).
- Provide support in a new environment until the person has become accustomed to it and can easily find his way around.
- Provide support when walking if needed.
- Use adaptive aids such as telephones with larger numerals, large print books, and magnifying glasses.
- Provide adequate handrails in stairwells and other areas where the person may need support.

Aging and the Gastrointestinal System

In older adults, the stomach produces less gastric juice which may lead to more frequent indigestion and ulcers. A decrease in saliva production may lead to gum disease. Aging causes decreased smooth muscle tone which means slower digestion and emptying of the stomach bowel. There is also less absorption of nutrients from food.

Support Strategies:

- Promote elimination through increased fluids, fiber and physical activity
- Observe for constipation
- Encourage slower eating with smaller, more frequent meals
- Avoid empty calories

Aging and the Genitourinary (Urinary/Reproductive) System

With age, bladder capacity and muscle tone decreases. The kidneys become less efficient and enlargement of the prostate is common.

Support Strategies:

- Observe for voiding patterns – increased or decreased frequency or changes in continence
- Observe for signs of infection – frequency urgency, accidents, discomfort, unusual odor or bleeding
- Encourage good hygiene practices

Aging and the Pulmonary System (Lungs)

Aging may cause lungs to become less elastic and therefore less able to take in oxygen. Breathing becomes less efficient and tolerance for exercise decreases. The lungs are less able to eliminate mucous because of changes in the respiratory tract and there may be a decreased cough reflex.

Protecting the Lungs

- Avoid smoking and second-hand smoke
- Encourage deep breathing, physical activity
- Help alleviate stress
- Encourage proper diet and enough fluids
- Watch for signs of infection (increased coughing, shortness of breath, colored sputum, increased confusion)

Aging and the Musculoskeletal System

Aging may cause a decrease in muscle mass, strength and tone. Joints show decreased mobility and bones become more porous and fragile. There is also an increased likelihood of developing arthritis.

Protecting the Musculo-Skeletal System

- Encourage independent movement and self-care
- Promote regular exercise
- Implement safeguards to prevent falls
- Promote safe use of mobility aids
- Provide seating that is comfortable, firm, and not too deep
- Ask health care provider about calcium and vitamin D supplements

Bowel Tracking

Agencies should have a bowel tracking system for all individuals who receive bowel related treatments so that agency staff and nurses can recognize when problems are arising. A bowel tracking system should include day/time of bowel movement, quantity of stool, and character of the stool.

Roles and Responsibilities

QIDP

- Recognize relevant risk factors or trends that may indicate a need for medical evaluation and changes in the treatment plan.
- Ensure the healthcare provider is presented this information when the individual is assessed.
- Ensure individuals who are being treated for constipation have a bowel tracking system in place and that all staff are trained in this tracking.
- Consider periodic bowel tracking for all individuals so the diagnosis of constipation is not overlooked.
- Must ensure that individuals who are able to be physically active have adequate opportunity to stay physically active.
- Ensure a meal program that provides good sources of dietary fiber.
- Every individual should have an area that addresses bowel elimination in the annual nursing assessment, and be included in the ISP as appropriate.
- For individuals treated with any medication for constipation, the ISP should reflect information from bowel tracking forms as well as how often a “PRN” medication (i.e. a suppository or enema) is used to treat the individual.

Bristol Stool Chart

There are seven types of stools (feces) according to the Bristol Stool Chart. The Bristol Stool Chart or Bristol Stool Scale is a medical aid designed to classify feces into seven groups.

The type of stool or feces depends on the time it spends in the colon. After feces is passed, what is seen the toilet bowl is basically the result of the persons diet, fluids, medications and lifestyle. The Bristol Stool Chart can be used to evaluate stools.

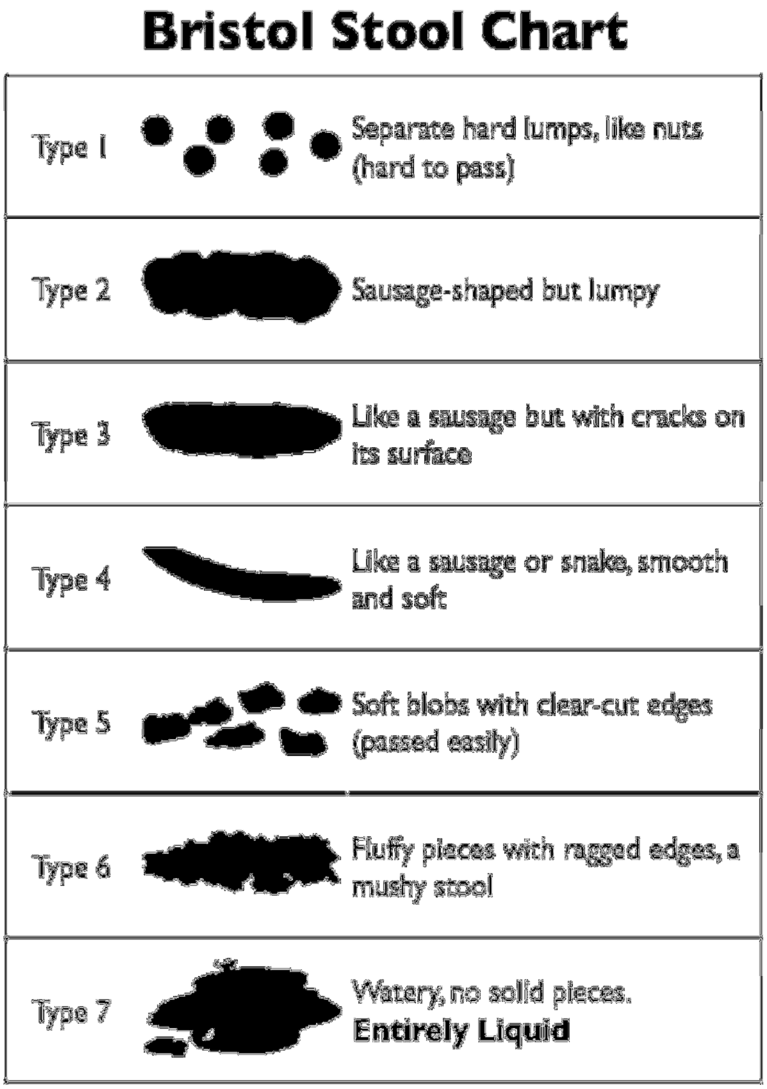
The Bristol Stool Chart shows seven categories of stool. Every person will have different bowel habits, but the important thing is that stools are soft and easy to pass – like types 3 and 4 on the following page.

Types 1–2 indicate constipation

Types 3–4 are ideal stools as they are easier to pass

Types 5–7 may indicate diarrhea and urgency.

The Bristol Stool Chart was developed by K. W. Heaton and S. J. Lewis at the University of Bristol and first published in the Scandinavian Journal of Gastroenterology in 1997.



Bristol Stool Chart

Type 1	Separate hard lumps, like nuts (hard to pass)
Type 2	Sausage-shaped but lumpy
Type 3	Like a sausage but with cracks on its surface
Type 4	Like a sausage or snake, smooth and soft
Type 5	Soft blobs with clear-cut edges (passed easily)
Type 6	Fluffy pieces with ragged edges, a mushy stool
Type 7	Watery, no solid pieces. **Entirely Liquid**

Choking From Bulk Forming Laxatives

Psyllium and polycarbophil are bulk forming laxatives and are known by trade names such as Metamucil, Perdiem, Genfiber, Fibercon, Equilactin and others. This type of laxative can cause choking and obstruction of the airway if they are not mixed according to the manufacturer's instructions. These products can quickly harden and may create a solid mass that can block the person's airway- creating a medical emergency that could result in death.

These laxatives must be mixed or taken with at least 8 ounces of water or juice. Powdered bulk forming laxatives should NEVER be mixed with food. Bulk forming fiber laxatives work by absorbing liquid in the intestines and swelling to create a softer, bulky stool that is easier to pass. Bulk forming laxatives come in powders, capsules or wafers.

Care must be taken to administer these medications properly. Powder laxatives must be mixed with at least 8 ounces of water or juice. If the mixture is too thick, add more liquid. After drinking the entire mixture, add a little more liquid to the same glass, swirl gently and drink right away to make sure you get the entire dose. If capsules are not taken with enough water, they may become stuck in the throat, swell and obstruct the airway. Wafers must be thoroughly chewed and taken with adequate water.

Urinary Issues

Some people may experience the frustration and embarrassment of urinary incontinence, the inability to hold urine. It is a common problem. It can affect young and old, men and women. The extent can range from an occasional leakage of urine, to a complete inability to hold any urine. When this happens, clothing gets wet, odors develop, and the person becomes uncomfortable. Being incontinent is beyond the person's control and dealing with it as a professional requires understanding, kindness and patience.

Common Types of Incontinence

- **Urge incontinence** is a sudden overwhelming need to urinate and the person is unable to control or stop the urine. Some common triggers are running water, hand washing and going out in the cold. When this happens, the person might lose urine very quickly or may leak slowly on the way to the toilet. Some people with urge incontinence also need to use the toilet frequently during the day and sometimes during the night.

- **Stress incontinence** occurs when you cough, laugh, sneeze or exercise.

- **Overflow incontinence** is when the bladder becomes full and starts to overflow.

- **Functional incontinence** occurs when a person is unable to get to the toilet, sometimes because of a physical disability such as arthritis. There is nothing wrong with their bladder. It is simply a matter of circumstances preventing the person from getting to the toilet.

Common Causes of Incontinence

There are a number of reasons someone you support may be incontinent. Incontinence can develop suddenly, be only temporary or be ongoing. Some causes include:

- Urinary tract infection, bladder infection or kidney infection
- Obesity or being overweight
- Caffeine or alcohol
- Enlarged prostate
- Constipation or stool impaction
- Stool impaction from severe constipation which causes pressure on the bladder
- Side effects of medications

Interventions that May Help with Incontinence include:

- Encourage people to use the toilet prior to sleep at night
- Make sure there is a lighted passageway to the toilet at night

Fecal Incontinence is loss of control of the bowels. This may lead to stool leakage from the rectum. Muscle damage is a common cause of fecal incontinence. Damage to the nerves that are responsible for rectal sensation is also a common cause. Diseases such as diabetes, spinal cord tumors and multiple sclerosis can cause nerve injury which can cause fecal incontinence.

Interventions for Fecal Incontinence

- Adequate fluid intake daily
- Regular exercise
- Positive mental outlook

Urinary Tract Infections

A urinary tract infection (UTI) is an infection anywhere in the urinary tract, the system of organs that collect and store urine and release it from the person's body. A UTI is caused by bacteria that can live in the digestive tract, the vagina, or around the urethra, which is the entrance to the urinary tract. These bacteria can enter the urethra and travel to the bladder and kidneys. E. coli bacteria in human intestines is the bacteria that causes many UTIs. Usually the person's body removes the bacteria during urination and people have no symptoms.

Risk factors for Urinary Tract Infections

- Use of a catheter
- Problems with the pelvic muscles and nerves as in Cerebral Palsy, spinal cord injury, or other neuro-muscular conditions
- Diabetes, HIV/AIDS, and Cancer
- Obesity
- Menopause
- Poor hygiene, such as inability to clean/wipe properly after bathroom use

S**ymptoms of UTI**

- Urine is dark, cloudy, or smells
- Dull pain in the back or sides (above the hip)
- Burning and pain with urination
- Feeling the urge to urinate often
- Bloody or pink-tinged urine
- Pain in the lower area of the belly
- Incontinence
- Nausea/Vomiting
- Confusion and Disorientation
- Fatigue and Drowsiness

Interventions/Prevention for UTI

- Hand washing before **and** after bathroom use
- Cleansing genital area front to back during baths/showers
- Wiping from front to back (especially in females) after bathroom use
- Keep well hydrated to prevent concentrated urine in the bladder which can grow bacteria

Overview of Self-Injurious Behavior

One of the most difficult health issues to manage is injury prevention from self-injurious behavior (SIB). The severity of injuries can vary from mild skin abrasions to life threatening head injuries. In persons with intellectual and developmental disabilities, the behavior may occur frequently and be directed at one part of the body, such as striking one ear with a fist or biting one hand. Suicide is uncommon in persons with intellectual and developmental disabilities and SIB.

Theories of causation are:

- An attempt to reduce stress and maintain homeostasis by using SIB as a diversion from stressful internal feelings or external situations. (Some experts view SIB as an extreme form of self-stimulating behavior)
- A way of blocking or controlling physical discomfort
- An attention seeking behavior that elicits response from others
- Results from boredom and the need for stimulation
- A disruption or chemical deficiency in the brain's neurotransmitter system
- A response to feelings of shame and worthlessness due to a history of trauma

Injuries that occur can range from mild calluses on one hand or wrist from biting to skull fractures and retinal detachments from repeated head banging. The more at risk the person is from tissue and organ damage, the more aggressive the intervention must be to stop or minimize the behavior.

Possible Interventions:

- Medical evaluation to determine if there is any physical cause (e.g., headache, earache, toothache, etc.)
- Therapy to address a history of trauma
- Distraction and diversion
- Psychoactive medications alone or in combination; no one specific medication class lessens or eliminates SIB in all persons
- Removal of rewards contingent on SIB
- Physical restraints when the behavior is intense. In some individuals, SIB occurs infrequently but is very intense when it occurs. Physical restraints such as mittens, wrist protectors and helmets can be worn during periods when SIB is intense to prevent injury.
- Combination of any or all of these methods.

Because of the complexity of SIB behavior, a behavior specialist is usually needed to help caregivers with interventions that may stop or minimize the behavior. If interventions are restrictive, the plan must be approved by the team. If any type of restrictive intervention is used, it must be approved by the agency's Human Rights Committee.

Discuss your agency's policies and procedures for addressing SIB

Infection Control

It is imperative to exercise good infection control procedures and to model those principles for the individual so that he/she will also practice those principles. Infection control promotes good health and dramatically reduces frequency of illness.

The most important guideline that the QIDP can stress is frequent and effective hand washing. Encourage hand washing:

- After toileting
- Before eating, drinking or smoking
- Before preparing food
- Before taking medication
- Before and after tooth brushing
- After handling unclean items
- After petting animals
- After blowing nose, or coughing/sneezing, etc.

Preventing the Occupational Transmission of Blood-borne Disease

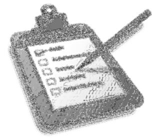
Healthcare-associated infections (HAIs) are infections caused by a wide variety of common and unusual bacteria, fungi, and viruses during the course of receiving medical care.
Wherever patient care is provided, adherence to infection prevention guidelines is needed to ensure that all care is safe care. This includes traditional hospital settings as well as outpatient surgery centers, long-term care facilities, rehabilitation centers, and community clinics. The information on this website is intended to inform staff concerning reducing the risks of contracting HAIs.

Current Regulations

All staff who directly support people with intellectual and developmental disabilities must complete blood-borne pathogen training annually. Four currently existing standards have been coordinated to provide an enforcement strategy to prevent the occupational transmission of blood-borne disease. These standards are:

29 CFR 1910.132 – Personal Protective Equipment
http://www.osha.gov/pls/oshaweb/owadisp.show_document?p_table=STANDARDS&p_id=9777
29 CFR 1910.22(a)(1) and (a)(2) – General Requirements/Housekeeping
http://www.osha.gov/pls/oshaweb/owadisp.show_document?p_table=STANDARDS&p_id=9714
29 CFR 1910.141(a)(4)(I) and (ii) – Sanitation; Waste Disposal
http://www.osha.gov/pls/oshaweb/owadisp.show_document?p_table=STANDARDS&p_id=9790
29 CFR 1910.145(f) – Specifications for Accident Prevention Signs and Tags
http://www.osha.gov/pls/oshaweb/owadisp.show_document?p_table=STANDARDS&p_id=9794

Emergency Protocols



Review your agency specific protocols

- Agency on-call system
- Activating 911 services

After contacting 911,

- **STAY CALM**, so that you can reassure the person and not add to fear and concern.
- **STAY WITH THE PERSON** until the emergency professionals arrive.
- **MAINTAIN AIRWAY**, if necessary by tilting the head back.
- **CONTROL BLEEDING** by application of pressure, or use of a tourniquet if necessary.
- **TREAT FOR SHOCK** by having the person lie down, loosen clothing, cover with a blanket, and seek medical attention.

Recommended Reading & Resources

Although we will try to cover a great deal of material with you today in class, the topic of medical supports is a broad one that requires continued study and attention throughout your career. We recommend the following resources as good places to start with regard to furthering your knowledge and understanding of this important topic.

- DHS Developmental Disabilities Nursing Manual
  http://www.oregon.gov/dhs/spd/provtools/nursing/ddmanual/all_sections.pdf
- DHS Developmental Disabilities Nursing Manual
  http://www.oregon.gov/dhs/spd/provtools/nursing/ddmanual/all_sections.pdf
- Medical Issues for Adults with Mental Retardation/Developmental Disabilities by *Carl V. Tyler, M.D.*
- PICA Behavior: A Short Overview by *Casey S. Nelson*

QIDP Professional TRAINING

Module 1: Introduction to the World of the QIDP
Module 2: Leadership and Communication
Module 3: Behavioral Supports
Module 4: Person Centered Planning
Module 5: Record Keeping
Module 6: Advocacy, Rights, and Resources
Module 7: Environmental and Safety Supports
Module 8: Medical Supports

Module 9: Rules and Regulations

Module Overview

Module 9 Introduction

Why are rules and regulations important to you, as a QIDP?
As a QIDP you have an obligation and responsibility to ensure that the rules and regulations that apply to your program and agency are followed. While you are not expected to be an expert in all regulations that apply to your agency, you are expected to have a basic understanding of those that apply to the program within which you work.

Objectives
Participants will be able to:

- Recognize the role of rules and regulations in promoting quality services for the individuals we serve.
- Identify the difference between Medicare and Medicaid.
- Explain the importance of Medicaid waivers and identify the rule and/or waiver that applies to the program in which they work.
- Distinguish between the regulatory bodies common to this industry.
- Know how to locate online the rules and regulations that govern this field.
- Outline agency-specific procedures for the implementation and control of governmental rules and regulations.
- Discuss the role of the QIDP in DHS or IDPH surveys.

RULES AND REGULATIONS

"Our lives begin to end the day we become silent

about things that matter."

- Martin Luther King, Jr.

Although some people may be inclined to think of rules and regulations as a nuisance or as something that "gets in the way" of delivering services, keep in mind they were first developed and continue to be used as one avenue of promoting quality services. Not all that long ago, people with intellectual and developmental disabilities were mistreated and not respected.

Failure to comply with rules and regulations can negatively impact:

- The safety and well-being of those served
- The quality of services provided
- Funding
- Licensure
- Staff
- Relationships with families, guardians and other agencies
- The credibility of our agency and staff

Medicaid Waivers

While Congress and the Centers for Medicare and Medicaid Services (CMS) set out the general rules under which Medicaid operates, each state runs its own program. Medicaid is a program that is not solely funded at the federal level. States provide up to half of the funding for the Medicaid program. In some states, counties also contribute funds. There are many services that can fall under Medicaid and some states support more services than other states. The most provided services are intermediate care for intellectually and developmentally disabled, prescription drugs and nursing facility care for under 21-year-olds.

Unlike Medicaid, Medicare is a social insurance program funded at the federal level and focuses primarily on the older population. Medicare is a health insurance program for people age 65 or older, people under age 65 with certain disabilities, and people of all ages with end stage renal disease. The Medicare Program provides Medicare Part A which covers hospital bills, Medicare Part B which covers medical insurance coverage, and Medicare Part D which covers prescription drugs.

The main criterion for Medicaid eligibility is limited income and financial resources, a criterion which plays no role in determining Medicare coverage. Medicaid covers a wider range of health care services than Medicare. Some people are eligible for both Medicaid and Medicare.

What is A Waiver?

Beginning in the 1980s, many states received waivers from the federal government to create Medicaid managed care programs. Under managed care, Medicaid recipients are enrolled in a private health plan, which receives a fixed monthly premium from the state. The health plan is then responsible for providing for all or most of the recipient's healthcare needs. Today, all but a few states use managed care to provide coverage to a significant proportion of Medicaid enrollees. As of 2014, 26 states have contracts with Managed Care Organizations (MCOs) to deliver long-term care for the elderly and individuals with disabilities.

The 1915(c) waivers are one of many options available to states to allow the provision of long term care services in home and community based settings under the Medicaid Program. States can offer a variety of services under a Home and Community Services (HCBS) Waiver program. Programs can provide a combination of standard medical services and non-medical services. Standard services include but are not limited to: case management (i.e. supports and service coordination), homemaker, home health aide, personal care, adult day health services, habilitation (both day and residential), and respite care. States can also propose "other" types of services that may assist in diverting and/or transitioning individuals from institutional settings into their homes and community.

Medicaid waivers provide states with some flexibility in determining the services they provide, who can provide the services and how health, safety and quality are determined. The state must make certain assurances to the federal government in order to have the waiver approved:

- Each person served must have an individual plan of care developed by qualified professionals
- Necessary safeguards must be taken to ensure the health and safety those in program
- Each person served has a free choice of qualified provider
- State must account for all funds; how monies are spent, for whom and for what services

Significant Court Decisions Impacting Disability Services

Wyatt v Stickney

In this landmark 1971 case, a federal court in Alabama held for the first time that people who are involuntarily committed to state institutions because of mental illness or developmental disabilities have a constitutional right to treatment that will afford them a realistic opportunity to return to society. The ruling led to sweeping reforms in the nation's mental health systems and the creation of minimum standards of care and rehabilitation for people with mental illness and developmental disabilities.

Olmstead v. L.C. & E.W.

The story of the Olmstead case begins with two women, Lois Curtis and Elaine Wilson, who had mental illness and developmental disabilities, and were voluntarily admitted to the psychiatric unit in the State-run Georgia Regional Hospital. Following the women's medical treatment there, mental health professionals stated that each was ready to move to a community-based program. However, the women remained confined in the institution, each for several years after the initial treatment was concluded. They filed suit under the Americans with Disabilities Act (ADA) in 1995 for release from the hospital.

In 2009, the Civil Rights Division launched an aggressive effort to enforce the Supreme Court's decision in *Olmstead v. L.C.*, a ruling that requires states to eliminate unnecessary segregation of persons with disabilities and to ensure that persons with disabilities receive services in the most integrated setting appropriate to their needs.

Ligas v. Hamos (Illinois)

The Ligas v. Hamos lawsuit was filed on July 28, 2005 on behalf of adults with developmental disabilities living in private, Illinois State-funded Intermediate Care Facilities for Persons with Developmental Disabilities (ICFs/DD) who want to move to community-based services or settings and on behalf of adults with developmental disabilities living at home who want community-based services or settings. In June 15, 2011, the Ligas v. Hamos Consent Decree was approved by the Court. This consent decree provides timelines for providing transition to individuals who wish to live in community-based residential setting.

Licensing & Regulations

The Illinois Department of Human Services, Bureau of Accreditation, Licensure & Certification (BALC) is responsible for licensing programs and services for persons with intellectual and developmental disabilities under Title 59 and 77 of the Illinois Administrative Code. After initial licensing, programs undergo annual review to ensure the existence of structural and procedural standards believed necessary for quality services.

BQM (Bureau of Quality Management) reviews compliance with other quality-related rules and guidelines of DHS, specifically those located in the provider contract(s) or in other relevant rules, such as Medication Administration (116).

QIDPs work across many different programs and are often responsible for work that directly correlates to regulatory requirements. Regulations for many programs are below:

Administrative Code: Title 59 Mental Health
Chapter I Department of Human Services
Part 50 Office of Inspector General investigations of alleged abuse or neglect in state-operated facilities and community agencies
Part 115 Community Integrated Living Arrangements
Part 116 Administration of Medication in Community Settings
Part 117 Family Assistance and Home-based Support Programs for Persons with Mental Disabilities
Part 119 Minimum Standards for Certification of Developmental Training Programs
Part 120 Medicaid home and community-based services waiver program for individuals with developmental disabilities

To find the full content of the Rules above go to www.ilga.gov/commission/jcar.
Click on Title 59 to find Part 50, 116, 117, 119 and 120. Clicking on “Part” will take you to that particular content.

Administrative Code: Title 77
Part 350 intermediate care for the developmentally disabled facilities code (ICFDD)

To find the full content of the Rules above go to www.ilga.gov/commission/jcar.
Click on Title 77 to find Part120. Clicking on “Part” will take you to that particular content.

Accreditation
In addition to state and federal standards of service, Illinois also requires that some Intellectual and Developmental Disabilities programs be accredited by national accrediting agencies. These agencies maintain their own structural and procedural standards and review programs independently of the Department of Human Services.

Deemed status has been granted for portions of department rules based on recognition of national accreditation standards adequately addressing the same principles. Therefore, to avoid duplication of reviews, BALC surveyors do not review the rule sections for which deemed status has been granted. Two of the most popular are:

- The Council on Quality and Leadership-CQL www.thecouncil.org
- Commission on Accreditation of Rehabilitation Facilities-CARF www.carf.org/home

Discuss deemed status as it applies to your agency.

Guardianship and Advocacy

Created in 1979, the Illinois Guardianship and Advocacy Commission protects the rights and promotes the welfare of persons with disabilities by providing legal representation, investigating complaints of rights violations and providing state guardianship.

The following website offers a comprehensive detail of the Guardianship and Advocacy Commission: http://www.illinois.gov/sites/gac/AboutUs/Pages/GuardFAQ.aspx

Discuss the role of guardianship as it relates to a person's day to day life.

Mental Health & Developmental Disabilities Code

The Mental Health and Developmental Disabilities Code addresses issues related to the rights of individuals with mental health and/or developmental disabilities. It covers such topics as money, property, mail, refusal of services, advocacy and many other topics. It is important for you to become familiar with this law as it relates to your role as a QIDP.

Office of Inspector General Investigations of Alleged Abuse or Neglect and Deaths in State-Operated and Community Agency Facilities (59 Ill. Adm. Code 50)

The Office of Inspector General (OIG) for the Department of Human Services (DHS) was "created to investigate and report upon allegations of the abuse, neglect, or financial exploitation of individuals receiving services within mental health facilities, developmental disabilities facilities, and community agencies operated, licensed, funded, or certified by the Department of Human Services." The rule is known as "Rule 50" because it is located in the Administrative Code, Title 59, Chapter 1; Part 50. The Hotline for reporting incidents of abuse, neglect and financial exploitation for the above individuals is: **1-800-368-1463**.

Adult Protective Services Act (320/ILCS 20)

The Adult Protective Services Act governs rules for reports of abuse, neglect and financial exploitation for adults 18-59 years of age with a disability or adults 60+ years of age who live in a **domestic living situation.** “Domestic living situation” means a residence where the adult with disabilities lives alone or with his or her family or a caregiver, or others, or other community based unlicensed facility. The Hotline for reporting incidents of abuse, neglect and financial exploitation for the above individuals is: **1-866-800-1409.**

Rules and Regulations

Title 59 Part 115 - CILA

Licensure and Certification Act [210 ILCS 135] is to license agencies for community residential programs known as Community Integrated Living Arrangements (CILA) for individuals with intellectual and developmental disabilities.
Discuss the following topics as they relate to Rule 115.

ISPs must be signed by guardians. Under what circumstances might this be delayed or not happen and how do you handle it?

Direct service employees must have a minimum of 80 hours of on the job training. What is your role in their training?

What is your role in fire and tornado safety training and drill?

What type of internal review processes does your agency maintain to ensure that the requirements for the CILA rule continue to be met?

Rules and Regulations

Title 59 Part 50 (Rule 50) Office of Inspector General Investigations of Alleged Abuse Or Neglect In State-Operated Facilities And Community Agencies

Office of Inspector General investigations of alleged abuse or neglect in state-operated facilities and community agencies.
Discuss the following topics as they relate to Rule 50.

How does your agency ensure that every staff member receives Rule 50 training and what is your role in that training?

Title 59 Part 116 - Medication Administration
This rule regulates the storage, distribution and administration of medications as well as the training of non-licensed staff in administration of medication.
Discuss the following topics as they relate to Rule 116.

In which programs does your agency train direct support employees to administer medications?

Discuss your agency's general practice with regard to medication storage.

Rules and Regulations

Title 59 Part 119 - Developmental Training

This rule regulates programs that provide developmental training to adults with intellectual and developmental disabilities. They are sometimes referred to as day programs.
D*iscuss the following topics as they relate to Rule 119.*

As a QIDP for a residential program how will you stay informed of a person's day program services? (vice versa)

How many different programs do the people that you will support participate in and are they within your agency or others? How will you stay informed of the many activities that the people you support are involved in?

Title 77 Part 350 - Intermediate Care Facilities for Individuals with Intellectual/Developmental Disabilities

This rule provides regulations for residential programs larger than CILAs.
Discuss the following topics as they relate to Rule 350.

How are evening and weekend community based activities scheduled and encouraged and what will be your role in them?

What is your agency's expectation for QIDPs with regard to amount of time spent in the residence and direct service staff on the job training for data collection?

Rules and Regulations

Review the list of rules and regulations below and determine if each is applicable to your agency and to your program.

Specific Rule / Regulation	Your Agency	Your Program
Those applying to Guardianship & Advocacy		
Rule 350		
Rule 115		
Rule 116		
Rule 119		
Confidentiality Act		
Reporting Regulations (Abuse & Neglect) Rule 50		
Council on Quality and Leadership		
Commission on Accreditation of Rehabilitation Facilities (CARF)		
Medicaid Waiver		
Centers for Medicare & Medicaid Services (CMS)		
Joint Commission on Accreditation of Healthcare Organizations (JACHO)		
Mental Health Code		
Those generated by Illinois Department of Public Health (IDPH)		

Reporting Regulations

A variety of situations may require you to make an official report. Discuss with your trainer and your class the responsibilities related to each of these situations. Add additional issues to the list and review all appropriate forms.

Situation	When to Report	Who Should Report	Where to Report	Time Frames for Reporting	Form Name/Number
Abuse					
Neglect					
Injury					
Critical Incidents					
Change in Status					
Admission					
Discharge					
Transfers					

Recommended Reading & Resources

Although we try to cover a great deal of material with you today in class, the topic of rules and regulations is a broad one that requires continued study and attention throughout your career. We recommend the following resources as good places to start with regard to furthering your knowledge and understanding of this important topic.

Guardianship	http://www.illinois.gov/sites/gac/Pages/default.aspx
Illinois State Board of Education	http://www.isbe.net/
Nurse Practice Act	http://nursing.illinois.gov/nursepracticeact.asp
HIPAA	http://hfs.illinois.gov/hipaa/
Americans with Disabilities Act	http://www.ada.gov/
Medicaid Waivers	http://www2.illinois.gov/hfs/MedicalPrograms/HCBS/Pages/default.aspx
Centers for Medicare/Medicaid	http://cms.gov/
Council on Quality and Leadership	http://www.thecouncil.org
JACHO	http://www.jointcommission.org
CARF	http://www.carf.org/home
Illinois Dept. Human Services (ILDHS)	http://www.dhs.state.il.us/page.aspx
Illinois Dept. Public Health (ILDPH)	http://www.idph.state.il.us/
Consumer Rights Illinois	http://www.illinoisattorneygeneral.gov/consumers/consumer_publications.html
Illinois Department of Labor	https://www.illinois.gov/idol/Pages/default.aspx
IL Health Care and Family Services (ILHCFS)	http://www2.illinois.gov/hfs/Pages/default.aspx
Illinois Adult Protective Services Act	http://www.ilga.gov/legislation/ilcs/ilcs3.asp?ActID=1452&ChapterID=31

Appendix A

Rules and Regulations: Where to Find Them

Rule Number	Title	Web Address
50	OIG Investigations of Alleged Abuse or Neglect in State-Operated Facilities and Community Agencies	www.ilga.gov/commission/jcar ▪ Click on 'Administrative Code' ▪ Click on Title 59 ▪ Click on Part 50
115	Standards & Licensure Requirements for Community-Integrated Living Arrangements	www.ilga.gov/commission/jcar ▪ Click on 'Administrative Code' ▪ Click on Title 59 ▪ Click on Part 115
116	Administration of Medication in Community Settings	www.ilga.gov/commission/jcar ▪ Click on 'Administrative Code' ▪ Click on Title 59 ▪ Click on Part 116
119	Minimum Standards for Certification of Developmental Training Programs	www.ilga.gov/commission/jcar ▪ Click on 'Administrative Code' ▪ Click on Title 59 ▪ Click on Part 119
350	Intermediate Care for the Developmentally Disabled Facilities Code (ICFDD)	www.ilga.gov/commission/jcar ▪ Click on 'Administrative Code' ▪ Click on Title 77 ▪ Click on Part 350
210 ILCS 30	Health facilities Abused and Neglected Long Term Care Facility Residents Reporting Act	www.ilga.gov/legislation ▪ Click on 'Compiled Statutes' ▪ Regulation; Chapter 210: Health Facilities ▪ Click on 210 ILCS 30
740 ILCS 110	Mental Health & Developmental Disabilities Confidentiality Act	www.ilga.gov/legislation ▪ Click on 'Compiled Statutes' ▪ Rights & Remedies; Chapter 740: Civil Liabilities ▪ Click on 110
405 ILCS 5	Mental Health & Developmental Disabilities Code	www.ilga.gov/legislation ▪ Click on 'Compiled Statutes' ▪ Health & Safety; Chapter 405: Mental Health ▪ Click on 405 ILCS 5