

QIDP Professional TRAINING



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Module 3: Behavioral Supports

Module 4: Person Centered Planning

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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.

It 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 addition, 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 can 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

Takeaways:

- 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.

Note: 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 CLAs. 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

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

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