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Strategies to Enhance the Quality of Life of Individuals with Intellectual and Developmental Disabilities: Training for ICF/ID Staff

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Introduction





The ICF/ID training is designed for direct support professionals (DSPs) who work in Intermediate Care Facilities serving youth and young adults with *intellectual and developmental disabilities* (I/DD). The purpose of the training is to provide ICF staff information, resources, and age-appropriate strategies to increase the independence and community integration of youth and young adults with I/DD.

Definition of Intellectual and Developmental Disabilities

The American Association on Intellectual and Developmental Disabilities defines I/DD as “characterized by significant limitations in both intellectual functioning and adaptive behavior as expressed in conceptual, social, and practical adaptive skills” (AAIDD, 2010, p. 1). In the context of this definition, DSPs must understand that providing supports for people with I/DD can be a complex and individualized process. Supports should be dynamic and should consider the *intellectual abilities, adaptive behaviors, health, participation, and contexts* as outlined by AAIDD (2010) below:

- **Intellectual Abilities.** DSPs should be aware that individuals differ in their ability to understand complex ideas, adapt to different environments, learn from experience, engage in different forms of reasoning, and overcome obstacles.
- **Adaptive behaviors.** Adaptive behaviors include conceptual, social, and practical skills that are learned and performed by individuals with I/DD in their daily lives. DSP should assess adaptive behavior based on an individual’s typical performance during daily routines and changing circumstances.
- **Health.** DSPs should understand how the individual effects of health and mental health on functioning can facilitate and inhibit engagement based on the types and quality of supports.
- **Participation.** Participation refers to the roles and interaction in home, work, education, leisure, spiritual, and cultural activities. DSPs should encourage participation in valid activities that are considered normative for an individual’s age group.
- **Context.** Context often determines what an individual is doing, where the person is doing something, when the person is doing something, and with whom the person is engaged. DSPs should consider contextual factors with a focus on inclusive education, living, and recreation/leisure settings.



Quality of Life Framework

DSPs must value, understand, and use strategies that promote *quality of life* (QOL) outcomes for people with I/DD. The idea of promoting QOL is important because we know that all people strive for the same basic QOL outcomes including *emotional, economic, and physical-well-being*. All people seek opportunities for *interpersonal relationships, social inclusion, and self-determination*.

Using a QOL framework to promote independence and community access is important because youth and young adults with ID/D are often marginalized and experience higher levels of segregation and isolation from peers without disabilities (Wilson et al., 2017) and segregation at school (McDonnel & Hunt, 2014). Youth and young adults with I/DD also experience poor independent living and poor employment outcomes (Winsor, et al., 2019). Because of these differences, DSPs must not only value the importance of community access and supports but must also have the capacity to meaningfully promote and teach the skills for youth and young adults with I/DD to access their communities.

This training is designed to provide DSPs with a basic understanding of how supports for individuals with I/DD have evolved over the years. The training will examine how to use person-centered planning and informed choice of youth and young adults with I/DD to promote self-determination and plan for independence and full community participation. The training is divided into seven self-paced online learning modules and this companion manual will serve as a reference guide for each of the online training modules.



Quality of Life Framework for Supporting Individuals with I/DD

- QOL is composed of the same factors and relationships for people with intellectual disabilities that are important to those without disabilities;
- QOL is experienced when a person's needs and wants are met and when one has the opportunity to pursue life enrichment in major life settings;
- QOL is primarily the perception of the individual that reflects the quality of life he/she experiences;
- QOL is based on individual needs, choices, and control; and
- QOL is a multidimensional construct influenced by personal and environmental factors, such as intimate relationships, family life, friendships, work, neighborhood, city or town of housing, education, health, standard of living, and the state of one's country (Schalock, et al., 2002).

Each module explores the following topics:

1	Policy Framework for Integrated Supports and Services
2	Rights and Privacy
3	Age-Appropriate Supports and Services
4	Informed Choice and Person-Centered Planning
5	Collaboration and Transition from School to Adulthood
6	Independent Living Skills Instruction
7	Positive Behavior Support



Module 1: Policy Framework for Integrated Supports and Services





The purpose of module 1 is to provide background information about Intermediate Care Facilities for Intellectual Disabilities (ICF/IDs) and provide an overview of specific legislation that has been enacted to improve independence, access, and community-based outcomes for people with disabilities.

At the end of this module, you will be able to:

- Describe the history of intermediate care facilities for individuals with I/DD.
- Describe the Social Security Act in relation to ICF/IDs and Home and Community-Based Services (HCBS) waivers.
- Describe the Rehabilitation Act for supported/customized employment and pre-employment transition services.
- Describe the Individuals with Disabilities Education Act (IDEA) for transition to adult living.
- Describe Title II of the Americans with Disabilities Act (ADA).
- Describe the Olmstead Decision as it relates to community options for people with disabilities.

The following table lists key terms you will need to know for Module 1.

Term	Definition
<i>Institutional bias</i>	Favoring an institutional setting over services being delivered in the home or community.
<i>Statutory requirements</i>	Requirement or rule imposed by a law or policy.
<i>Meaningful access</i>	Access to the community that is purposeful and individualized.
<i>Most significant disabilities</i>	A person with a severe physical or mental impairment that affects one or more functional abilities.
<i>Competitive integrated employment</i>	Employment that is paid at least at minimum wage and is commensurate with other employees doing similar work and is done in the general community with coworkers who may or may not have a disability.



Congregate settings

A setting primarily or only used by individuals with disabilities.

History and Background of ICF/IDs

Prior to the 1970's, the residential options for people with I/DD were often large institutional facilities that were funded by states. These facilities were overcrowded with poor living conditions. In 1965, Medicaid was authorized, and resulted in the availability of federal funding for I/DD services. At that time, Medicaid became the major source of public funding for long-term services and supports for people with I/DD. In 1971, changes to the Social Security Act allowed states to use Medicaid to pay for services in an Intermediate Care Facility for Mental Retardation. These facilities are now referred to as Intermediate Care Facilities for Intellectual and Developmental Disabilities (ICF/IDs). This provision required states' institutions meet federal compliance standards to receive federal funds.

Need to Know

[Rosa's law](#) (Public Law 111-256, 2017), required all references to the term "mental retardation" in federal law to be changed to "intellectual disability."

Video:

<https://www.jointherevolution.org/50-game-changers/rosas-law>

To qualify for Medicaid reimbursement, ICF/ID's must be certified and comply with federal standards in specific areas, including:

1. Management
2. Client protections
3. Facility staffing
4. Active treatment services
5. Client behavior and facility practices
6. Health care services
7. Physical environment and dietetic services

See <https://www.law.cornell.edu/cfr/text/42/part-483/subpart-B>



Facts About ICF/IDs

Approximately 73,885 individuals with intellectual disabilities live in intermediate care facilities for individuals with intellectual disabilities (ICF/IDs) in 6,084 ICF/IDs across the country (Larson et al., 2020). Roughly 7% (4,919) of these individuals are under 21 years old.

596

Individuals with I/DD live in private ICF/ID in Utah

64 individuals are under 21

Utah annual expenditure per person

\$62,070

CMS Shift in Services

The Centers of Medicare and Medicaid Services (CMS) recognize there has been a major shift in the way services are provided to individuals with I/DD. The emphasis is now on people with I/DD living in their own homes, controlling their own lives, and engaging in local communities (CMS, n.d). This shift is reflected in many position statements from advocacy organizations and major pieces of legislation that are designed to improve individualized, integrated, and appropriate services and supports to individuals with disabilities.

Position Statements

<https://www.aaidd.org/news-policy/policy/position-statements/community-living-and-participation>

The Social Security Act

The Social Security Act, signed into law in 1935, was designed to protect U.S citizens against the “hazards and vicissitudes of life” ([FDR, Online Library, n.d.](#)).The two primary outcomes in the initial Act were: Title I, Grants to States of Old-Age Assistance and Title II, Federal Old Age benefits. These titles were designed to protect the financial security of older citizens. In 1965, Medicaid was added into the amendments of the Act. Medicaid became the major source of public funding for long-term services and supports for people with ID.



In 1971, revisions to the Act provided an optional Medicaid benefit that allowed states to provide comprehensive and individual rehabilitation services to individuals through ICF/IDs. The Social Security Act was criticized for having an “institutional bias”, or, favoring institutions (Tanis, 2020; ASAN, n.d.). In addition, many recommendations have been made about how to create community-based services or alternatives to services provided in ICF/IDs.

Medicaid Waivers

Social Security attempted to address the “institutional bias” in the 1981 amendments to the Social Security Act and authorized the Medicaid Home and Community Based Services (HCBS) waiver program. HCBS waivers were specifically created to address this institutional bias so that Medicaid programs could provide coverage for services in homes and communities. HCBS waivers are intended to complement the regular services that are available through the Medicaid state plan. A Medicaid waiver waives certain statutory requirements, like requiring services to be provided in an institutional setting. This allows a state to offer Medicaid beneficiaries the option of receiving services in their homes and communities. The flexibility in the design and delivery of Medicaid home and community-based services allows states to specifically design service options that are customized to the unique needs of people in the state.

UTAH HCBS Waiver Programs

- Acquired Brain Injury Waiver
- Aging Waiver (for individuals 65 and older)
- Community Supports Waiver
- Community Transitions Waiver
- Medically Complex Children’s Waiver
- New Choices Waiver
- Physical Disabilities Waver
- Waiver for Technology Dependent Children

<https://medicaid.utah.gov/ltc/>



The CMS Final Settings Rule

The Centers for Medicare and Medicaid Services (CMS) issued the Home and Community-Based Waiver Services (HCBS) [Final Settings Rule \(CMS2249-F/2296-F\)](#) in 2014. The [Final Settings Rule](#) was designed to enhance the quality of HCBS programs and increase opportunities for individuals with disabilities to have meaningful access to integrated community settings.

Five Qualities for HCBS Waiver Settings

1. The setting is integrated in and supports full access to the greater community;
2. The setting is selected by the individual from among setting options;
3. The setting ensures individual rights of privacy, dignity and respect, and freedom from coercion and restraint;
4. The setting optimizes autonomy and independence in making life choices; and
5. The setting facilitates choice about services and who gives them.

42 CFR Section 441.301 (c)(4)

According to the CMS, the Final Settings Rule requirements establish an outcome-oriented definition that focuses on both the nature and quality of an individual's experience. These requirements are designed to maximize opportunities for individuals with disabilities to have access to the benefits of community living and the opportunity to receive services in the most integrated setting. The Final Settings Rule allows states to develop a transformation process to meet these new requirements. One of the challenges of meeting these requirements, however, is ensuring that changes set forth by the Final Settings Rule promote meaningful access to the integrated community (Friedman & Spassiani, 2017).

The Rehabilitation Act

The Rehabilitation Act of 1973, as amended, is the major legislative source for programs and initiatives administered by the Rehabilitation Services Administration (RSA). The Act was a significant body of legislation for people with disabilities. It recognizes that individuals with disabilities encounter various forms of discrimination in areas such as employment, housing, public accommodations, education, transportation, communication, recreation,



institutionalization, health services, voting, and public service.

The Rehabilitation Act: Civil Rights

The Rehabilitation Act is a civil rights and funding statute. The civil rights component is outlined under Section 504. Under this section, individuals with disabilities cannot be excluded from participation in, denied benefits, or subjected to discrimination in programs receiving federal funds.

Civil Rights Provision Section 504

“No otherwise qualified individual with a disability in the United States, as defined in section 705(20) of this title, shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance or under any program or activity conducted by any executive agency or by the United States Postal Service” ([29 U.S.C § 794](#)).

The Rehabilitation Act: Programs

Supported and Customized Employment. The Rehabilitation Act authorizes the funding of vocational rehabilitation programs such as supported employment. The purpose of supported and customized employment is to assist people with the most significant disabilities to achieve their employment goals. The 2014 Rehabilitation Act defines supported employment as “competitive integrated employment, including customized employment, or employment in an integrated work setting in which individuals are working on a short-term basis toward competitive integrated employment, that is individualized and customized consistent with the strengths, abilities, interests, and informed choice of the individuals involved, for individuals with the most significant disabilities—for whom competitive integrated employment has not historically occurred” ([29 U.S.C § 705](#)).



Supporting Youth and Young Adults with Significant Disabilities

As part of the 2014 amendments to the Rehabilitation Act, states must allocate half of the supported employment state grants to support youth with the most significant disabilities (up to age 24) ([34 CFR §363.22](#)). In addition, these youth may receive extended services (i.e., ongoing supports to maintain an individual in supported employment) for up to 4 years.

The 2014 Rehabilitation Act Amendments also provided the first federal definition of Competitive Integrated Employment (CIE). The Act defines CIE as...work that is performed on a full-time or part-time basis (including self-employment) - for which an individual (a) earns at least minimum wage, (b) is paid commensurate wages and benefits, (c) is in a location where the employee interacts with other persons without disabilities, and (d) is presented with opportunities for advancement ([29 U.S.C § 705](#)).

Pre-employment Transition Services. The 2014 amendments to the Rehabilitation Act emphasize a much larger role of state rehabilitation agencies in youth with disabilities transition from school to adult life. These amendments stipulate that 15% of each state's public vocational rehabilitation funds must now be used for pre-employment transition services. Pre-employment transition services include:

- Job exploration counseling,
- Work-based-learning,
- Counseling on post-secondary education programs,
- Workplace readiness training, and
- Instruction in self-advocacy.

Only students with disabilities may receive pre-employment transition services. A student with a disability is defined as an individual with a disability who is not younger than the earliest age for the provision of transition services under the Individuals with Disabilities Education Act (IDEA) and is not older than 21 years of age; or is student who meets the Section 504 definition of an individual with a disability.



The Americans with Disabilities Act of 1990, as Amended

The Americans with Disabilities Act (ADA) was signed into law in 1990 and amended in 2008. This legislation guarantees important civil rights for people with disabilities and ensures that people with disabilities have equal opportunities for access and employment. The ADA extends the civil rights, non-discrimination mandate of the Rehabilitation Act to private employers and organizations that do not receive federal financial assistance. The ADA prohibits discrimination against people with disabilities in *Title I; employment, Title II; public services, Title III; public accommodations, Title IV; transportation, and telecommunications, and Title V, miscellaneous provisions.*

Title II Integration Mandate

“a public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities” (28 C.F.R. § 35.130(d)).

It is important for DSPs, parents, and individuals with disabilities to understand the Title II integration mandate. The integration mandate influences the way programs and services are provided to people with disabilities and it enables individuals with disabilities to interact with persons without disabilities to the fullest extent possible.



Segregated and Integrated Settings Information [U.S. Department of Justice \(2011\)](#)

What is an integrated setting under ADA and Olmstead?

The “most integrated setting” is defined as “a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible.” Integrated settings are those that provide individuals with disabilities opportunities to live, work, and receive services in the greater community, like individuals without disabilities.

What is a segregated setting?

Segregated settings include, but are not limited to: (1) congregate settings populated exclusively or primarily with individuals with disabilities; (2) congregate settings characterized by regimentation in daily activities, lack of privacy or autonomy, policies limiting visitors, or limits on individuals’ ability to engage freely in community activities and to manage their own activities of daily living; or (3) settings that provide for daytime activities primarily with other individuals with disabilities.

The Olmstead Decision

The Olmstead decision of 1999 was a U.S. Supreme Court Case that examined segregated placements of people with disabilities (Olmstead v. L.C., 119 S.Ct. 2176. 1999). The case centered around two women with developmental disabilities and mental illness who were voluntarily admitted in the Georgia Regional Hospital, psychiatric unit. The two women requested that they be discharged from the hospital and be provided with community-based services. The hospital staff agreed that the women could be placed in community-based settings. However, the State of Georgia was slow in developing community placements and the women were placed on a waiting list for services. The Court’s decision has important implications for people with disabilities because it set forth a three-part test to determine if community placement is appropriate for people with disabilities:



Three Part Test

1. The State's treatment professional has determined that community placement is appropriate;
2. The transfer from institutional care to a less restrictive setting is not opposed by the affected individual; and
3. The placement can be reasonably accommodated, considering the resources to the state and the needs of others with mental disabilities (119 S. Ct. at 2181)

The Individuals with Disabilities Education Act

The Education for All Handicapped Children Act (EAHCA), was enacted in 1975 to provide students with disabilities the opportunity to receive a public education. Since its inception, the EAHCA made free and appropriate public education (FAPE) available to students with disabilities who were previously excluded from public school.

Basic Rights of EAHCA

1. A free, appropriate public education (FAPE).
2. An education in the least restrictive environment (LRE).
3. An individualized education program (IEP)

(Huefner, 2006)

In 1990 the act was revised and renamed the Individuals with Disabilities Education Act (IDEA). The revisions explicitly addressed school district responsibilities for helping students transition from school to adult life. The Act required that a student with disabilities' IEP contain a statement of transition services. Providing timely and effective transition services is one way to prepare students with disabilities for integrated employment, inclusive activities, and independent living, and will help youth with disabilities prepare for the demands of adult living. In 2004, IDEA was amended to further refine secondary school requirements for transition (see Module 4).



Module 1 Summary

Module 1 introduced the policy framework for providing individualized, integrated, and appropriate services and supports to individuals with disabilities. The module provided a review of key legislation designed including The Rehabilitation Act of 1973, as amended; The Education for All Handicapped Children Act of 1975, as amended; The Social Security Act of 1935, as amended; and the Americans with Disability Act of 1990, as amended. The module also reviewed the 1999 Supreme Court Olmstead Decision as it relates to the Court's holding that entities must provide community-based services to people with disabilities.

Key Takeaways

- The Rehabilitation Act, as amended, addresses both civil rights and funding. The Act outlines that a qualified individual with a disability shall not be excluded, denied, or discriminated under any program or activity receiving Federal financial assistance. Supported and customized employment are added services under the act.
- The Americans with Disabilities Act integration mandate influenced the way programs and services are provided to people with disabilities and it enables individuals with disabilities to interact with persons without disabilities to the fullest extent possible.
- The Individuals with Disabilities Education Act recognizes transition services as meaningful inclusive education and that employment experiences are directly linked to quality adult outcomes. Providing timely and effective transition services is one way to prepare students with disabilities for integrated employment, inclusive activities, and independent living.
- The Olmstead Decision noted that unjustified isolation of people with disabilities is a form of discrimination.



Reflection Questions

- Given the intent of legislation to improve integrated outcomes for people with disabilities, what are ways that you can assist people with I/DD to engage more meaningfully in community environments?
- How do you think the ADA integration mandate impact the services and supports you provide individuals with I/DD?



Module 2: Ensuring Rights and Privacy





In the first module we identified the federal law and a key Supreme Court decision that guarantee individuals’ civil rights and equal access to education, communities, and supports. This module reviews Utah’s administrative code (administrative code are laws) related to ICF/ID and reviews the Code of Ethics for DSPs which ensure an individual’s rights. The module ends with a discussion about supporting people in ways that do not limit an individual’s overall quality of life.

At the conclusion of this module, you will be able to:

- Identify the rights of people with disabilities guaranteed in Utah.
- Describe the principle of normalization and how to apply it to the services you provide.
- Follow the National Alliance for Direct Support Professionals (NADSP) Code of Ethics

The following table lists key terms you will need to know for Module 2.

Term	Definition
<i>Quality of life</i>	The overall quality of a person’s life based on health, safety, and ability to participate and enjoy things that are important to the person.
<i>Basic human rights</i>	Rights entitled to each individual without discrimination.
<i>Exploitation</i>	Unfairly benefitting from someone’s work and/or treating someone poorly.
<i>Principle of Normalization</i>	Having a typical or “normal” routine of life that is compared to others without a disability.
<i>Restraint and seclusion</i>	Includes physical restraints and seclusion from others.
<i>Age-appropriate</i>	Using a person’s chronological age to determine activities and/or tasks.

Rights of People with Disabilities

Utah Administrative Code R432-152 requires ICF/IDs to use and follow policies and practices about individuals with I/DD in many areas, including (a) rights; (b) finances(money); (c) communication (talking with others); and (d) staff



treatment (how staff care for people with disabilities). As a DSP supporting people with disabilities daily, it is important that you understand how these policies impact your role in supporting individuals with I/DD.

The rights shown in R432-152 ensure that individuals with disabilities living in an ICF/ID have the same rights as all U.S. Citizens. Many are basic human rights and activities that most people without disabilities take for granted every day. These rights guarantee individuals are respected as people and not viewed only as clients. As part of this guarantee, individuals are encouraged to file official complaints, grievances, and make recommendations for changes in policies and procedures to staff and outside representatives without reprisal (getting back at someone) by ICF/ID administrators or staff. The following summary gives an overview of these rights.

For the full code, visit

<https://rules.utah.gov/publicat/code/r432/r432-152.htm>

Healthcare



The ICF/ID must inform individuals, parents or legal guardians, of an individual with I/DD's current health status. The individual with I/DD has the right to know about any medical condition; potential treatments and risks associated with those treatments; and the right to refuse treatment. Examples could include needing antibiotic for an ear infection; a recommendation for removing tonsils due to chronic strep throat; or being placed on birth control due to irregular menstrual cycles. Individuals with disabilities will also receive active treatment to reduce any dependency on unnecessary drugs.



Safety

Individuals shall not be physically, verbally, sexually or emotionally abused, or punished. Examples would include being hit, punched, grabbed; being called bad names or racial slurs; being bullied/intimidated, threatened or insulted; being humiliated; or being isolated from others (such as being required to sit alone or not being allowed to join activities). In addition, individuals with I/DD will not be given unnecessary drugs or unnecessarily be physically restrained. An example would include giving medication to sedate (make them sleepy) individuals to enforce an early bedtime.



Communication Privacy

Basic rights to privacy include the ability to send and get unopened mail. Individuals with disabilities also must have access to telephones and may have privacy for incoming and outgoing local and long-distant calls. Exceptions to private calls may be made if written in their individual program plans. The staff must ensure that individuals have the right to communicate and meet privately with people of their choice including attorneys or religious clergy. For example, staff cannot require they sit with the person when they meet with their priest or bishop.

Personal Privacy



Individuals are given the right to privacy during personal treatment and caring for their personal needs (which includes sexual masturbation). Married couples living in the same facility may reside together as a couple. In addition, individuals have the right to own and use their own clothes and personal belongings. Staff are required to ensure individuals are wearing their own clothes each day.



Group Activities

Individuals with disabilities must have opportunities to participate in social and community group activities with same-aged peers. Examples would include attending a high school, college or professional sporting or cultural event;



attending community dances and festivals; or participating in their preferred activities with their same-aged peers. They may also be given the opportunity to practice their religious beliefs and go to religious worship services without being forced to perform any religious activity. For example, an individual may choose to attend mass but not to kneel or receive communion.

DSPs should remember that the preferred activities of individuals will differ, as will their preferences for who is in a group together. Although a 10-year-old boy may enjoy a sporting event, his preferred group is likely to be his same-aged peers.

Free from Exploitation

Individuals with I/DD shall not be told to join in publicity events, fund raising activities, movies or any activity that would/could exploit the person. For example, a minor child cannot be required to have their picture taken and used for publications (such as calendars or brochures) including social media posts without permission of the parent or legal guardian.

In addition, individuals with I/DD may not be told to perform services for the facility. If an individual chooses to work for the facility, they must be paid wages commensurate to a person without a disability performing that work skill. For example, if individuals who work in a cafeteria are paid the federal minimum wage, the individual with I/DD should be paid at the same rate.

Finances

Individuals with disabilities should be taught how to manage their finances (money) to the best of their ability and be allowed to do so. Money skills are categorized as an independent living skill and DSPs should understand how to use



systematic instruction to teach financial skills (see module 4). For example, DSPs can teach an individual with I/DD to identify and count coins and/or bills; pay for purchases using next-dollar strategy; or create and follow a budget. The Utah law also requires that any of an individual with I/DD's money or personal valuables kept within the ICF must be given to the individual upon request.



Communication with Individuals, Parents, and Guardians

There are two types of communication with individuals with I/DD, parents, and guardians which are addressed in the Utah Code R432-152: (a) communication for treatment; and (b) maintaining relationships outside of the ICF/ID.

Healthcare

R432-152 specifies that ICF/IDs encourage the individual to talk to doctors/nurses/counselors and be involved in their healthcare, and if applicable their legal guardian or parent during the treatment. If an individual is younger than 18-years-old, their parent should be included in treatment plans when appropriate and possible. In the event of a serious illness, accident, death, abuse or unauthorized absence (person runs away or doesn't come back when they are supposed to), the administration should contact the individual's parent or guardian immediately. R432-152 requires that ICF/ID staff respond promptly to all communication from family and friends.



Social Relationships

The quality of life of individuals with severe and profound I/DD is impacted by having many friends and family members involved in their lives (Bramston et al., 2005; Campo et al., 1997; Lunsky & Benson, 2001; Miller & Chan, 2008; Renty & Roeyers, 2006). Due to the limitations of living in an ICF/ID and that some individuals with I/DD cannot call or write to a person independently, staff attitudes and encouragement for talking/writing to family and friends is important in keeping relationships

(Campo et al., 1997). R432-152 requires ICF/ID staff to encourage visits by family, close friends, legal guardians and advocates at any reasonable hour. Prior notice of a visit is not required as long as the visit does not interfere with the individual's



rights or another individual's privacy. The ICF/ID treatment team may decide a visit is not good for the individual and not allow visits in some situations, for example, if the parent has abused the child and the visit would cause additional trauma (harm; cause person to be scared or upset). Parents or guardians are encouraged to visit with their child in any area of the facility that gives direct client care service to an individual. Again, the visit must not interfere with individual's and other individuals' rights to privacy. In addition, R432-152 requires that staff promote frequent home visits, trips, or vacations with the individuals and their friends and family members. Staff helping these community activities with friends and family have been identified by researchers as factors resulting in increased life satisfaction for people with disabilities (Miller & Chan, 2008).

Staff Treatment of Individuals with Disabilities

DSPs must ensure the rights and protections of individuals with I/DD meet the seven requirements outlined in R432-152.



These requirements stipulate the following:

1. The facility shall develop and implement written policies and procedures that prohibit mistreatment, neglect, or abuse of a client.
2. Staff of the facility shall not use physical, verbal, sexual or psychological abuse, or punishment.
3. Staff shall not punish a client by withholding food or hydration (water, drink) that contribute to a nutritionally adequate diet.
4. The facility shall prohibit the employment of individuals with a conviction or prior employment history of child, client abuse, spouse abuse, neglect or mistreatment.
5. The facility shall ensure that all allegations of mistreatment, neglect or abuse, or injuries of unknown source, are reported immediately to the administrator and to other officials in accordance with 62A-3-302 through established procedures.
6. The facility shall have evidence that all alleged violations are thoroughly investigated and shall prevent further potential abuse while the investigation is in progress.
7. The results of all investigations shall be reported to the administrator or designated representative and to other officials within five working days of the incident and, if the alleged violation is verified, appropriate corrective action shall be taken.

Improvements in laws and policies may be needed, but those can only establish a framework. Real human connections – infused with positive values are what will make all the difference in the lives of people with disabilities.

-Ed Burke

Other Considerations

DSPs should also understand that defining how to appropriately interact with individuals with I/DD is not always outlined in law. The way DSPs interact and provide supports can improve or hurt an individual's overall quality of life. A key to providing supports to individuals with disabilities is the "principle of normalization" (Nirje, 1969). While this principle has been around for over 50



years, and we have replaced the term “mental retardation” for “intellectual and developmental disabilities”, it still has application to the services and supports DSPs provide.

Principle of Normalization

“Normalization means a normal rhythm of day for the retarded. It means getting out of bed and getting dressed even when you are profoundly retarded and physically disabled. It means eating under normal circumstances: sometimes, during the span of the day, you may eat in large groups, but mostly eating is a family situation which implies rest, harmony, and satisfaction. A normal daily rhythm also means not having to go to bed earlier than your peers because you are mentally retarded, not earlier than your younger sisters and brothers, or not too early because of lack of personnel. Facilities must also give consideration to the individual's need for a personal rhythm, allowing him to break away occasionally from the routine of the group.....the normalization principle also implies a normal routine of life. Most people live in one place, work or attend school somewhere else, and have leisure-time activities in a variety of places. Consequently, it is wrong when a retarded person, for example, has his training classes, his structured therapies, and his recreation activities in the same building that serves also as his "home" (p.1).

Limit the Use of Restraint and Seclusion

DSPs should use least restrictive measures when supporting a person who have behaviors. Using least restrictive measures in a respectful and dignified manner aligns with the improving the quality-of-life theme of this training. The importance of using least-restrictive measures is important because of the negative results from with using more restrictive measures such as physical restraints (for example tying a person in a chair or using a rope/leash to keep person from running ahead of group) and seclusion (keeping a person from others for example requiring a person to sit at a table alone). Physical restraints and seclusion can result in physical injury, psychological and/or emotional harm, and problem behaviors occurring at the same or increasing frequency (Finke, 2001; Vollmer et al., 2011; Walker & Pinkelman, 2018). Further, restraints and seclusion are often used inappropriately, are overused, dehumanizing, and dangerous. Any behavioral intervention should not infringe on dignity or rights of individuals with I/DD.



DSPs should make a concerted effort to prevent restraining or secluding by using escalation techniques and positive behavior supports (See Module 7).

Sadly, there also have been recent examples where physical restraints have resulted in the death of the individual with a disability (<https://www.npr.org/2018/12/09/675145052/school-where-student-with-autism-died-violated-state-regulations-officials-say>)

Include Individuals in Conversations

You can show respect of individuals with I/DD by including them in conversations. For example, asking questions directly and looking the person in the eye rather than looking to other staff to answer your questions. You will also be able to model this respect in public in many ways. For example, when ordering at a



restaurant, the waitress may look at staff and ask, “What does he want?” In this instance, you could turn your body facing the individual you are supporting and wait for the individual to reply. This is a non-verbal cue (hint) that you are not talking for the person and the individual will be speaking for themselves. In addition, it is important to not talk negatively about an individual with I/DD with other staff when the individual with I/DD is in the room. For example, do not talk about a behavior when there is a DSP shift change in front of the individual with I/DD.

Develop Strategies to Communicate with People who are Non-Verbal

DSPs should ensure that individuals who are non-verbal are given meaningful time to communicate their feelings and wants and needs. DSPs should look at how the individual is using non-verbal actions and behaviors as a way to communicate. Develop strategies to help an individual communicate such as communication books and choice boards and/or utilize assistive technology.



Give the Individual Time to Process

When you ask questions of people you support, it is essential you give adequate processing time of the question so the individual may respond themselves. Processing time refers to giving time to think about the question and understand what is being asked plus time to think of a response and then say the words. Recommendations range from five seconds for college students without disabilities to 15 seconds to 2 minutes for elementary age children (McCarthy, 2018). You may have to fight your own internal discomfort to answer for the individual, but it is essential the individual is given the time to speak for themselves.

Assume Competence

Assume that all individuals with I/DD have the ability to be in many places and learn new skills. Do not assume that the way a person looks and communicates is how they think and feel. TASH, an international advocacy association focused on people with the highest support needs, gives guidance on strategies for presuming competence.



Please read and reflect on these strategies.

<https://tash.org/wp-content/uploads/2019/03/Strategies-Presuming-Competence.pdf> (TASH, 2007).

Age-Appropriate Expectations

As a DSP, you should have age-appropriate expectations of the person with a disability. You may be in a position where you support both children and adults with disabilities. In these situations, you should strive to develop activities or make living arrangements that are age appropriate. For example, if a resident is 10-years-old they may be interested in playing on the playground. This is an activity that typical 10-year-olds do; a 40-year-old playing on a children's playground is not age appropriate, it is not a typical activity for a single, 40-year-old man.

Age-Appropriate Activities

Activities should be based on a person's interest that match their age. For example, any nine-year-old child would have difficulty sitting quietly watching a



romantic comedy movie for an hour and a half. It is more appropriate the child watch an age-appropriate movie with their same age-peers and laugh with their friends. In contrast, another example would be for an 18-year-old person with I/DD to dress up and go tricker-or-treating which is an activity appropriate for pre-teens; in this example it would be more appropriate for this person to wear a costume while handing out candy rather than going door-to-door.

Limit Large Group Activities

DSPs should be aware that the community interest of individuals with I/DD are not all similar. Community activities should be based on an individual's interest and needs and not be based on ease of transportation or time constraints. For example, do not arrange a large group activity, consisting only of people with I/DD to attend a community function such as the "festival of trees," or bowling. Social inclusion happens when people are not segregated or in a large group. For example, when at a community dance, it is unlikely that a dozen people with disabilities staying in a group would be talked to by non-disabled people. However, if two people with disabilities were at a dance, it is more likely that people will talk to them and dance with them.

Ensure Appropriate Living Arrangements

Living arrangements should be age appropriate. For example, a child with an intellectual disability should not share a room or a bathroom with an adult. If an individual lives with a roommate, the individual should have an opportunity to choose a roommate of similar age. Placing a person in a room merely because there is an open bed is not a person-centered placement or helping the person's quality of life.

Code of Ethics

The National Alliance for Direct Support Professionals (NADSP) Code of Ethics (2016) may guide DSPs on their work and support of people with disabilities and ensure their rights, lead self-directed lives, and be included in their communities. Although we will be highlighting the contents of the document, we encourage you to read and discuss the [Code of Ethics](#) with your supervisor. The NADSP identifies nine core principles of the code of ethics for DSPs. As a DSP, you should read each principle as a commitment or oath to the people with disabilities you support.

When working with children, the National Association for the Education of Young Children (NAEYC) also a code of ethical conduct which may give guidance on your work with children. This code is based on the understanding that



childhood is a “unique and valuable stage” of human development. Although we are highlighting specific ideals and principles of the NAEYC Code, we encourage you to review the entire [Code of Ethical Conduct and Statement of Commitment](#). When working with children, the foundation of positive learning and development outcomes is based on individual relationships with children that recognizes their individual strengths, qualities, and potential while recognizing their vulnerability and dependence on adults. As a DSP it is important that you support the rights of each child to play and learn in positive and social environments that are age-appropriate for children with and without disabilities that respects each child’s culture, language, and ethnicity (NAEYC, 2011).

NADSP’s nine core principles of the code of ethics for DSPs

- My first allegiance is to the person I support; all other activities and functions I perform flow from this allegiance.
- I will commit to promoting the emotional, physical, and personal well-being of the people I support. I will encourage growth and recognize the autonomy of those receiving support while being attentive and energetic to reducing the risk of harm.
- I will support the mission and vitality of my profession to assist people in leading self-directed lives and to foster a spirit of partnership with the people I support, other professionals, and the community.
- I will safeguard and respect the confidentiality and privacy of the people I support.
- I will affirm the human rights as well as the civil rights and responsibilities of the people I support. I will promote and practice justice, fairness, and equity for the people I support and the community as a whole.
- I will respect the human dignity and uniqueness of the people I support. I will recognize each person I support as valuable and promote their value within communities.
- I will assist the people I support to develop and maintain relationships.



Module Summary

This module reviewed laws related to rights and privacy of individuals with I/DD who live in an ICF/ID rights including healthcare, communication privacy, personal privacy, group activities, free from exploitation, finances, and communication to maintain relationships. The National Alliance for Direct Support Professionals has a Code of Ethics which provide guidance for providing quality services. The Code includes DSP providing: person-centered supports; physical and emotional well-being; integrity and responsibility; confidentiality; justice, fairness and equity; respect; and relationships.

Key Takeaways

- All people deserve a quality of life that matches their normal daily rhythms.
- People with disabilities have rights that must be recognized and ensured by staff.
- People with disabilities should be supported to have community-based experiences based on their individual interests and preferences.
- The Code of Ethics should be followed by all DSPs to ensure people with disabilities are given the same rights as all American citizens.
- Childhood is an important developmental state which requires us to acknowledge their dependence on adults and their vulnerability.
- Providing children with a positive playing and learning environment is facilitated by respectful and age-appropriate activities.

Reflection Questions

- How have you helped individuals with I/DD communicate with family members?
- In what ways do you support children to communicate differently with their family than a middle-aged person?
- How have you developed community-based activities for an individual with I/DD based on interests, preferences and age?



- What are three ways you treat pre-teens differently from teenagers? 20-year-olds? Or senior citizens?

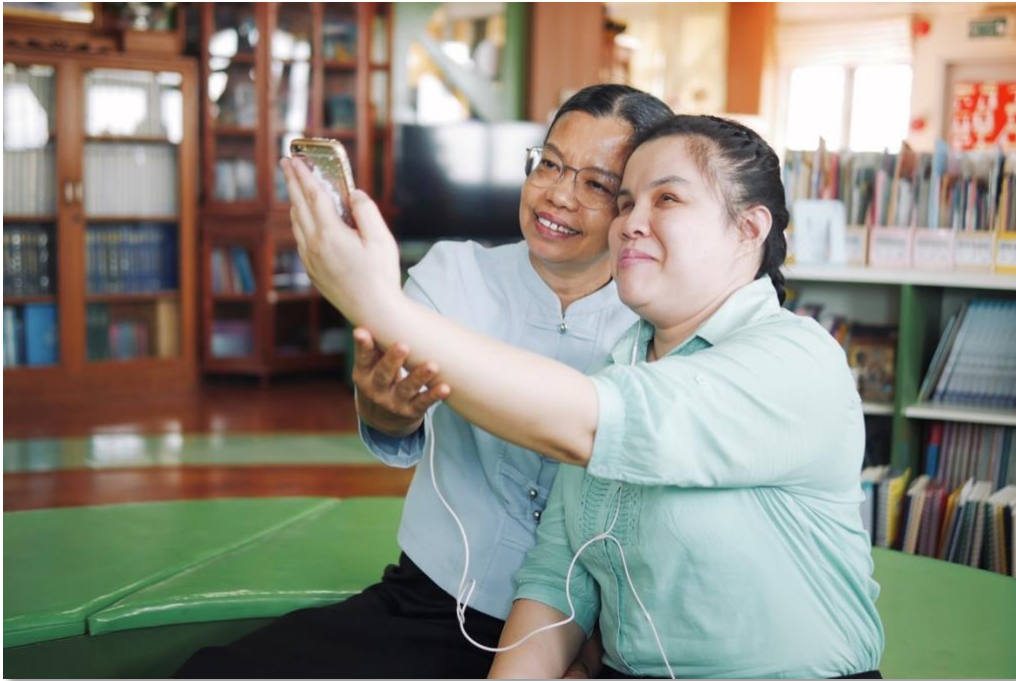
Self-Reflection

Ask yourself:

1. Do you listen to the children and youth you support?
2. Do you give youth time to express their feelings?
3. Do you allow the youth to make choices, even if bad choices?
4. Do you praise the child when they do a good job?
5. Do you ask children to perform tasks that are the same what children their age without disabilities are doing?
6. Do you tell the youth that you care about them?
7. Do you criticize the children and youth you support?
8. Do you criticize youth harshly when they misbehave?



Module 3: Age-Appropriate Supports and Services





The purpose of module 3 is to provide DSPs with information about how to ensure services and supports for youth, teenagers, and young adults are age appropriate. The module will explore how to appropriately support different age groups.

At the end of the module, you will be able to:

- Describe why it is important to use an individual’s chronological age to make decisions about supports.
- Describe age-appropriate strategies to support elementary-age individuals with I/DD.
- Describe age-appropriate strategies to support adolescents with I/DD
- Describe age-appropriate strategies to support young adults with I/DD.

The following table lists key terms you will need to know for Module 3.

Term	Definition
<i>Chronological age</i>	The actual age of an individual.
<i>Mental age</i>	The age of someone’s mental or physical performance compared to individual without disabilities’ chronological age.
<i>Augmentative and alternative communication</i>	Alternative ways of communication to replace or supplement speech.
<i>Age-appropriate</i>	Using a person’s chronological age to determine activities and/or tasks.
<i>Adolescent</i>	Children aged 10-18.
<i>Young adult</i>	Adults aged 18-25.
<i>Self-determination</i>	The attitude and/or ability to make choices for ourselves without external influence or interference.



Introduction

DSPs working in ICF/IDs may work with children, teenagers, and young adults with I/DD. Each age group engages in different developmental tasks and skills. Services and supports should be developed according to a person’s age and individualized support needs. One common issue that arises when supporting individuals with I/DD is professionals often default to an individual with I/DD’s mental age rather than an individual’s chronological age to develop services and supports. The idea of mental age was traditionally used as a way to express a child’s intellectual development; an individual’s mental age represents the average performance of another individual without disabilities chronological age. For example, a 16-year-old- young adult who has a mental age of 5.5 years is perceived to perform similar to a child who is 5.5 years. Unfortunately, relying only on the mental age of an individual often results in low expectations and services and supports that are not always age-appropriate.

As we previously indicated in Module I, the AAIDD describes intellectual disability as a significant limitation in intellectual functioning and adaptive behavior as expressed in conceptual, social, and adaptive skills. The AAIDD outlines five specific assumptions for this definition that DSPs should understand are listed in the table 3.1.

Table 3.1

AAIDD Five Assumptions	
Assumption 1	Limitation in present functioning must be considered with the context of community environments typical of the individual’s age, peers, and culture.
Definition	The standards against which the individual’s functioning are compared are typical community-based environments, not environments that are isolated or segregated by ability. Typical community environments include homes, neighborhoods, schools, businesses, and other environments in which people of similar age ordinarily live, play, work, and interact.
Assumption 2	Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioral factors.
Definition	In order for assessment to be meaningful, it must take into account the individual’s diversity and unique responses. The



individual's culture or ethnicity (including language spoken at home), nonverbal communication, and customs that might influence assessment results, must be considered in making a valid assessment.

Assumption 3 Within an individual, limitations often coexist with strengths.

Definition

This means that people with I/DD are complex human beings who likely have certain gifts as well as limitations. Like all people, they often do some things better than others. Individuals may have the capabilities and strengths that are independent of their I/DD (e.g., strengths in social or physical capabilities, some adaptive skill areas, or one aspect of an adaptive skill in which they otherwise show an overall limitation).

Assumption 4 An important purpose of describing limitations is to develop a profile of needed supports

Definition

Merely analyzing someone's limitations is not enough and that specifying limitations should be the team's first step in developing a description of the supports the individual needs in order to improve his or her functioning.

Assumption 5 With appropriate personalized supports over a sustained period, the life functioning of the person with an intellectual disability generally will improve.

Definition

If appropriate and personalized supports are provided to an individual with ID, improved functioning should result. A lack of improvement in functioning can serve as a basis for reevaluating the profile of needed supports.

DPSs should consider these assumptions when supporting children, teenagers, and young adults with I/DD as their support needs will shift according to chronological age, context, and environment.



Age-Appropriate Strategies to Support Youth with I/DD

Youth (5-12 years old) progress through a number of critically important developmental tasks and skills including developing social relationships and social skills and learning and developing age-appropriate independent and self-care skills.

Developing Social Relationships and Skills

Developing social relationships and social skills is a critical developmental task for youth with and without disabilities. During this time, youth begin to develop friendships and the skills necessary to maintain these friendships. Youth also learn important playtime and sharing skills (Smart, 2012). As outlined in the AAIDD's assumptions above, "limitation in present functioning must be considered with the context of community environments typical of the individual's age, peers, and culture." Because these early experiences help shape the way a youth engages with other individuals across developmental stages, it is important that youth with I/DD have meaningful opportunities to engage in structured and unstructured school and community activities with same-age peers with and without disabilities.



DSPs can support and encourage the development of social relationships through the person-centered planning process. DSPs should also work with parents and guardians to determine how to create meaningful interactions by asking basic questions, such as:

- With whom does the child have relationships and friendships outside of the ICF?
- Who does the child like to spend time with outside of the ICF?
- What type of community-based activities does the child like to do?

Communication is one of the barriers to meaningful interactions between peers. To help facilitate interactions, the DSP should assess the youth's communication and social skills to determine what skills need to be targeted for support/instruction and how to develop personalized supports that can be sustained.



Figure 3.1 gives examples of areas to assess for communication and socialization.

Once a DSP has assessed the communication and social skills of child, the DPS can then develop instruction, supports, and specific accommodations to facilitate meaningful social skills. For youth who do not have verbal communication skills, DSPs should determine augmentative and alternative communication (AAC) devices that can be used to facilitate meaningful interactions. In the past, communication devices were commonly used to articulate preferences and have conversations with others. The American Speech-Language-Hearing Association explains that there are two types of AAC: unaided systems and aided systems.

American Speech-Language-Hearing Association Definitions of AAC

Unaided Systems

You do not need anything but your own body to use unaided systems. These include gestures, body language, facial expressions, and some sign vocabulary.

Aided Systems

An aided system uses some sort of tool or device. There are two types of aided systems—basic and high-tech. A pen and paper is a basic aided system. Pointing to letters, words, or pictures on a board is a basic aided system. Touching letters or pictures on a computer screen that speaks for you is a high-tech aided system. Some of these speech-generating devices, or SGDs, can speak in different languages.

Refer to https://www.asha.org/Practice-Portal/Professional-Issues/Augmentative-and-Alternative-Communication/#collapse_2 for resources on how to develop AAC for individuals you support.



Figure 3.1
Areas to Target for Instruction and Support

Communication and Socialization Checklist					
Communication			Social Skills		
	Yes	No		Yes	No
• Expresses continuation or more			• Responds to the presence and interaction of others		
• Makes choices when provided options			• Initiates social interaction		
• Makes requests			• Sustains social interaction		
• Expresses rejection/refusal			• Terminates social interaction		
• Express greeting/goodbyes			• Distinguishes interaction with different people (family, friends, acquaintances, strangers)		
• Sustains communication with others			• Maintains socially acceptable behavior		
• Initiates communication with others			• Accepts assistance from others		
• Responds to questions					
• Asks questions					
Notes:			Notes:		

Note: Adapted from Giangreco, M. F., Cloninger, C. & Iverson, V. (2005). *Choosing outcomes and accommodations for children: A guide to education planning for students with disabilities*. 2nd edition. Baltimore, MD, Paul H. Brooks

Developing Age-Appropriate Independent and Self-Care Skills

An important development task for youth with I/DD is learning skills for to be more independent such as drinking and eating, using utensils, dressing and undressing, using the restroom, washing hands, brushing hair, recognizing dangerous situations, using crosswalks, etc. DSPs should assess what a youth with I/DD needs to learn to become more independent in these areas. Module 6 will review how DSPs can use the ecological assessment framework to assess and teach these skills.



Age-Appropriate Communication

DSPs should use simple sentences and age-appropriate vocabulary and provide clear expectations when interacting with youth with I/DD. When supporting children, refrain from using vocabulary and phrases which they may misinterpret. Youth with I/DD and may interpret words literally. Therefore, saying common idioms (such as save your breath; bite your tongue; and, pulling your leg) should not be used because they can cause confusion. Sarcasm and words/phrases with double meanings may also be difficult for youth, individuals with autism, and individuals that English is a second language to interpret correctly and should not be used.

Using Visual Supports

When youth are asked to engage in a sequence of tasks, using visual cues are ways to provide support to the youth and allowing them to perform the task independently. There are multiple strategies which may be used by a DSP. You may find that some strategies work well for some youth and not others. Providing visual supports of real pictures may make instructions or requests clearer to youth. A real picture allows the child to see what you are asking of them rather than showing a drawing which may be misinterpreted by the youth. The picture may also help the child recall what you are asking of them. In this example, this youth is being told the schedule of where they are going to be. A visual reminder may be helpful to prepare youth what tasks and activities are scheduled throughout the day. Figure 3.2 gives an example of visual reminder of a schedule.



Figure 3.2.



Age-Appropriate Strategies to Support Teenagers with I/DD

The developmental tasks for teenagers with I/DD shifts as they physically mature and prepare for emerging young adult roles. DSPs should develop age-appropriate supports and services that align with the developmental tasks and skills for this age group. Important considerations for teenagers include developing social skills, developing self-regulation skills, understanding and supporting physical development and sexual maturity, developing skills for independence, and developing a vocational identity.



Developing Social Skills/Teenagers

The social skills of adolescent and young adults begin to shift to emerging skills needed to engage in school, work, and community-based recreation and leisure environments. When a young adult with I/DD does not develop certain social skills or adaptive skills to engage in multiple environments, it may limit access to these environments. There are number of adaptive social skill areas that DSPs can assess and develop supports for teenagers and young adults (Paraschiv & Olley, 1999). Figure 3.3 lists these areas. As you examine these areas, consider ways in which an adolescent or young adult who does not have verbal communication can use these skills.



Figure 3.3
Adaptive Social Skills Areas for teenagers and young adults.

<p>Basic Social Skills</p> <p>Starting and maintaining a conversation Asking questions Saying thank you Giving and receiving complements Introducing oneself</p>	<p>Problem Solving</p> <p>Asking for help Following directions Dealing with conflicts Asking for permission</p>
<p>Self-Advocacy</p> <p>Knowing personal rights Advocating for personal needs and concerns</p>	<p>Boundaries</p> <p>Understanding physical boundaries Understanding sexual boundaries Communicating personal boundaries</p>

Paraschiv and Olley (1999) recommend specific strategies to assist and teach individuals learn these skills:

- Engage in active learning of the skill. Learn by doing in applied environment.
- Uses natural reinforcement. Let the individual experience positive results for engaging in the appropriate social skills.
- Use individual instruction. Develop individualized programs to teach these skills.

It is important to consider that these skills will not develop in isolation. Social skills are learned skills that need to be taught in context. DSPs should look for meaningful opportunities to teach individualized skills and provide opportunities for the individuals to practice.

Developing Self-Determination Skills

Self-determination skills are important skills for teenagers and young adults (Carter et al., 2013). Self-determination is directly correlated to improved quality of life because an individual with I/DD makes decisions that directly impact their life (Wehmeyer & Field, 2007).



Definition of Self-Determination Wehmeyer (1992)

“The attitudes and abilities required to act as the primary causal agent in one’s life and to make choices about one’s actions free from undue external influence or interference” (p.305)

According to Wehmeyer & Field (2007), the components of self-determination include:

- Choice making
- Decisions making
- Problem solving
- Goal setting and attainment
- Self-regulation and self-management skill
- Self-advocacy and leadership skills
- Self-awareness
- Self-knowledge

A DSP can help facilitate self-determination of teenagers with I/DD by teaching and supporting each of the skills above in applied contexts. Teaching and supporting these self-determination skills is important for teenagers and young adults because this age group is expected to engage in a variety of educational, community, and vocational settings. In fact, research suggests that teaching choice making, decision making and problem-solving skills improves community outcomes, improves vocational tasks, improves the capacity of individuals to identify abusive social interaction, and improves options for meaningful recreation and leisure options (Wehymer & Field, 2007).

The National Center on Secondary Education and Transition (Bremer et al., 2003) developed a tip sheet for promoting self-determination (Table 3.1). DSPs should reference this sheet when facilitating self-determination.



Table 3.1
NSCET's Tip Sheet for Promoting SD

Promoting Self-Determination in Youth with Disabilities: Tips for Families and Professionals	
<p>Promote Choice Making</p> <ul style="list-style-type: none">• Identify strengths, interests, and learning styles;• Provide choices about clothing, social activities, family events, and methods of learning new information;• Hold high expectations for youth;• Teach youth about their disability;• Involve children and youth in self-determination/self-advocacy; opportunities in school, home, and community;• Prepare children and youth for school meetings;• Speak directly to children and youth;• Involve children and youth in educational, medical, and family decisions;• Allow for mistakes and natural results;• Listen often to children and youth.	<p>Promote Self Advocacy</p> <ul style="list-style-type: none">• Encourage communication and self-representation;• Praise all efforts of assertiveness and problem-solving;• Develop opportunities at home and in school for self-advocacy;• Provide opportunities for leadership roles at home and in school;• Encourage self-advocates to speak in class;• Teach about appropriate accommodation needs;• Practice ways to disclose disability and accommodation needs;• Create opportunities to speak about the disability in school, home, church, business, and community.
<p>Encourage Exploration of Possibilities</p> <ul style="list-style-type: none">• Promote exploration of the world every day;• Use personal, tactile, visual, and auditory methods for exploration;• Identify young adult mentors with similar disabilities;	<p>Facilitate Development of Self-Esteem</p> <ul style="list-style-type: none">• Create a sense of belonging within schools and communities;• Provide experiences for children and youth to use their talents;• Provide opportunities to youth for contributing to their families, schools, and communities;



- Talk about future jobs, hobbies, and family lifestyles;
- Develop personal collages/scrap books based on interests and goals;
- Involve children and youth in service learning (4H, AmeriCorps, local volunteering).

- Provide opportunities for individuality and independence;
- Identify caring adult mentors at home, school, church, or in the community;
- Model a sense of self-esteem and self-confidence.

Promote Reasonable Risk Taking

- Make choice maps listing risks, benefits, and results of choice;
- Build safety nets through family members, friends, schools, and others;
- Develop skills in problem solving;
- Develop skills in evaluating results.

Develop Goal Setting and Planning

- Teach children and youth family values, priorities, and goals;
- Make posters that reflect values and are age-appropriate;
- Define what a goal is and demonstrate the steps to reach a goal;
- Make a road map to mark the short-term identifiers as they work toward a goal;
- Support children and youth in developing values and goals;
- Discuss family history and culture--make a family tree;
- Be flexible in supporting youth to reach their goals; some days they may need much motivation and help; other days they may want to try alone.

Encourage Problem Solving

- Teach problem solving skills;
- Allow ownership of challenges and problems;
- Accept problems as part of healthy development;
- Hold family meetings to identify problems at home and in the community.;
- Hold class meetings to identify problems in school;

Help Youth Understand Their Disabilities

- Develop a process that is directed by youth for self-identity: Who are you? What do you want? What are your challenges and barriers? What supports do you need?
- Direct children and youth to write an autobiography;
- Talk about the youth's disability;
- Talk about the youth's abilities;



- Allow children and youth to develop a list of self-identified results.
- Involve children and youth in their IEP;
- Use good learning style inventories and transition assessments;
- Identify and utilize support systems for all people.

Supporting Physical Development and Sexual Maturity

DSPs should understand and positively support the physical development and sexual maturity of teenagers and young adults with I/DD. Teenagers and young adults will experience many physical, sexual, and emotional changes from a period roughly between ages 10-21. Figure 3.4 gives a



timeline for the stages of adolescence adapted from Healthchildren.org (2019).

Figure 3.4.

Timeline for Development

Timeline for Development		
Age	Stage	Description
10-13	Early Adolescence Development & Growth	<ul style="list-style-type: none"> • Body changes, including hair growth under the arms and near the genitals, breast development in females and enlargement of the testicles in males. • Many girls may start their period at around age 12, on average 2-3 years after the onset of breast development.
10-13	Early Adolescence Concrete Thinking	<ul style="list-style-type: none"> • Things are either right or wrong, great or terrible, without much room in between. It is normal at this stage for young people to center their thinking on themselves (called "egocentrism").



10-13	Early Adolescence Need for Privacy	<ul style="list-style-type: none">• Early teenagers explore ways of being independent from their family. In this process, they may push boundaries and may react strongly if parents or guardians reinforce limits.
14-17	Middle Adolescence Physical Changes Interest in Sexual Exploration	<ul style="list-style-type: none">• Males typically start their growth spurt, and puberty-related changes continue. Males may have some voice cracking, for example, as their voices lower.• Some develop acne.• Physical changes may be nearly complete for females, and most girls now have regular periods.• Teenagers begin to explore their sexual identity• Adolescent males and females typically explore sex and sexuality through masturbation.• May engage in sexual activity with partners
19-21	Late Adolescence	<ul style="list-style-type: none">• Physical development complete and full adult height

Given the adolescence timeline, DSPs should develop age-appropriate and respectful strategies to support adolescent development, including: (a) teaching proper hygiene skills, (b) teaching feminine hygiene skills, (c) allowing for privacy for sexual exploration, and (d) teaching about private and public space. It is important to remember that because adaptive skill deficits of teenagers with I/DD, many of skills will need to be taught. Teaching and supporting these skills should always be implemented with professionalism and respect. Many of these skills can be taught using the strategies discussed in Module VI. An example of how female researchers taught feminine hygiene skills (changing sanitary napkins, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4893027/>) to individuals with disabilities in the presence of their mothers is described below. (Veazey et al., 2016). The researchers developed a 16-step task analysis (TA) and used prompting strategies that will be discussed in Module VI. This analysis and corresponding



research demonstrate that hygiene skills can be respectfully taught to individuals with I/DD.

TA to Teach Sanitary Skills

1. Walks to the bathroom.
2. Pulls down underwear below knees and sits on toilet.
3. Removes soiled sanitary napkin from underwear.
4. Wraps soiled sanitary napkin in toilet paper.
5. Disposes of sanitary napkin in the garbage can.
6. Removes soiled underwear.
7. Wipes vaginal area at least once with toilet paper to remove residual blood and drops paper in toilet.
8. Removes clean underwear from basket near the toilet.
9. Puts underwear on and pulls up to her knees.
10. Opens clean sanitary napkin from basket near the toilet.
11. Disposes of outer covering in the trash can.
12. Fastens sticky side of sanitary napkin lengthwise in underwear and presses into place.
13. Pulls up underwear and outer clothes.
14. Flushes toilet.
15. Washes hands.
16. Grabs underwear by the waistband and places it into the washing machine.

In regard to sexual education for individuals with I/DD, DSPs should teach specific skills, such as, healthy boundaries about appropriate touching and hugging, inappropriate and appropriate sexual language, inappropriate and appropriate times for masturbation, and sexual rights. DSPs should be cognizant of the fact the individuals with I/DD have the right to explore sexuality without judgement of staff; the role of the staff is to teach appropriate times and places to engage in this exploration. There are a number of resources that can help DSP provide age-appropriate, respectful strategies for sexual education.

- Vehmas, S. (2019). Persons with profound intellectual disability and their right to sex. *Disability and Society*, 34, (4), 519-539.



- Davis, T., Machalicek, W., Scalzo, R., Kobylecky, A., Campbell, V., Pinkelman, S., Chan, J., & Sigafoss, J. (2016). A review and treatment selection model for individuals with developmental disabilities who engage in inappropriate sexual behavior.
- *Association for Behavior Analysis International*, 9 (4), 389-403.
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5118249/>
- Sexual Resource Center for parents.
 - http://www.srcp.org/for_some_parents/developmental_disabilities/the_specifics/mastDD.html
- Respect Ability.
 - <https://www.respectability.org/resources/sexual-education-resources/>

Module 3 Summary

Module 3 provided information about how to provide age-appropriate services and supports. DSPs should take steps to ensure that supports and services are provided to individuals with I/DD based on chronological and not mental age. DSPs should also ensure that youth and teenagers with I/DD are taught skills that align with the developmental tasks and skills the person's chronological age. Finally, age-appropriate supports and services should be used to enhance an individual's strengths and interests.

Key Takeaways

- Limitation in present functioning must be considered with the context of community environments typical of the individual's age peers and culture.
- Social skills are learned best in real-life settings.
- Self-determined individuals make important life choices.
- Teenagers should be taught healthy boundaries about appropriate touching and hugging, inappropriate and appropriate sexual language, inappropriate and appropriate times for masturbation, and sexual rights.



Module 4: Informed Choice and Person-Centered Planning





This module gives information about person-centered planning (PCP) and services to ensure youth, teenagers, and young adults with I/DD are actively involved in planning their long-term and short-term goals. This module will explore the use of PCPs to develop meaningful activities that are tailored to the individuals' unique strengths and interests. This module will help the DSP understand the relationship between PCP, informed choice, and supported decision making which are key to improving the youth's quality of life.

At the conclusion of the module, you will be able to:

- Understand self-advocates and their families' goals for equality
- Understand the difference between systems-centered vs. person-centered services.
- Describe the PCP and why it is important to quality of life.
- Describe how PCP services and programming results in informed choice.
- Describe supported decision making and its process in supporting the independence of youth with disabilities as they become adults.

The following table lists key terms you will need to know for Module 4.

Term	Definition
<i>Informed Choice</i>	Being able to make an independent decision based on information given, real-life experiences, and examples.
<i>Capacity</i>	The mental and/or physical ability to make decisions and provide for oneself.
<i>Self-sufficiency</i>	Independently being able to provide one's basic needs financially and emotionally such as food, shelter, and safety.



Introduction

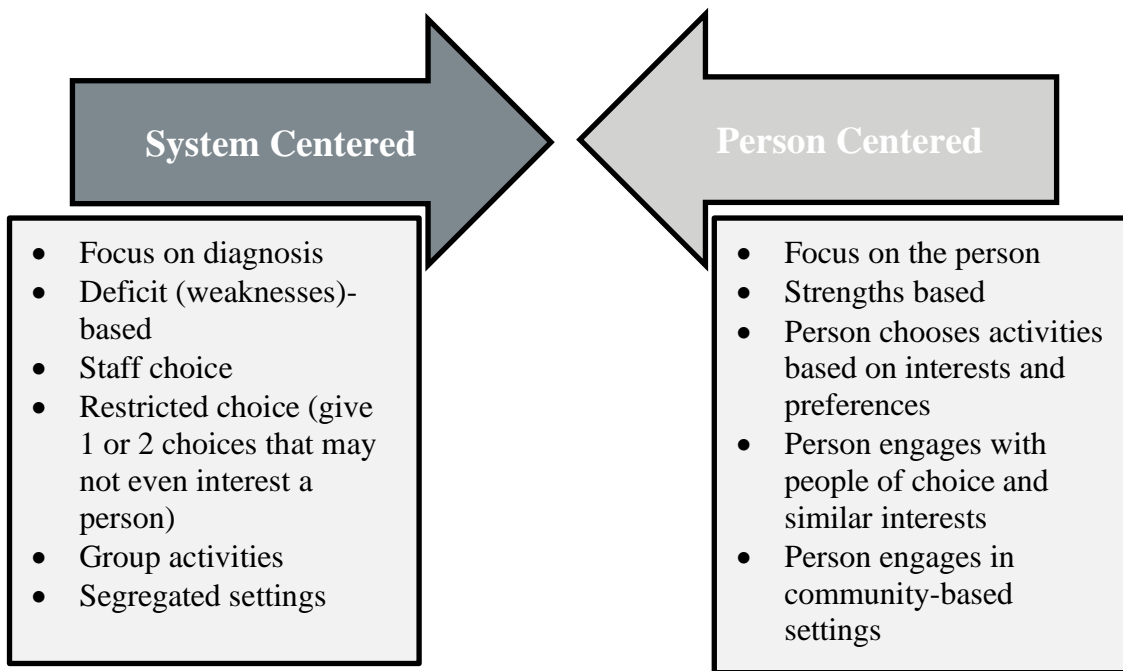
The practices shown in this module are based on the idea that informed, independent decision-making is a learned skill. DSPs play a key role in helping youth with I/DD learn to make daily choices and informed decisions about their lives. Supports to make informed decisions shift as the individual with I/DD learns these critical skills. The opportunities to gain multiple experiences and practice daily decision making cannot begin at age 18, it must start at younger ages and build over time to more complex decisions in getting ready for adulthood. Self-advocates and families with disabilities have led the movement for improving the quality of services for people with disabilities. By sharing their lived experiences and advocating for equality, people with disabilities assist all of us to understand the perspectives of people with disabilities and their preferences for supports. One advocacy effort centers around informed choice and legal capacity. Laws and policies have helped and encouraged DSPs to support the informed choice of individuals with I/DD. A new support paradigm is emerging requiring DSPs and agencies who support individuals with I/DD to recognize that all people have the ability to make informed choices in their lives.

Person-Centered Planning Process

To support youth with disabilities with making informed choices, the DSP can use the PCP process. PCP is a way to help individuals with I/DD strengthen their ability to make meaningful, informed choices about their futures. The PCP process focuses on the person rather than their disability. As shown in the Figure 4.1, the PCP approach contrasts with the system-centered approach that traditionally focused on the individual's diagnosis and deficits. Providing person-centered supports is the first requirement of the NADSP Code of Ethics. The Code states that to provide person-centered supports DSPs must "recognize the unique culture, social network, circumstances, personality, preferences, needs and gifts of each person...[which are] the primary guides for the selection, structure, and use of supports for that person" (NADSP, 2016, p.4).



Figure 4.1
Evolution of the PCP Process



Adapted from O'Brien & O'Brien; 2000; Taylor & Taylor, 2013; Trainor, 2007; Werner, 2012.

Identifying person-centered supports begins with the PCP process. PCP recognizes that the individual with a disability and their families are the experts and should be given the respect and dignity to make decisions (Ciccarello & Henry, 2014). PCP is a flexible process which is led by the person with a disability and includes a planning team made up of people important to the person and who know the person best (including family members, friends, neighbors, community members) and professionals. PCP focuses on the person's strengths, interests, preferences, support needs to develop goals with the person (O'Brien & O'Brien; 2000; Taylor & Taylor, 2013; Werner, 2012). A PCP may focus on whole-life planning or address one area such as individualized supports, housing, or employment. Although PCP does not quickly fix problems, when PCP is developed, the person's outcomes should include (a) increased community presence (being in the community); (b) more community activities and relationships; (c) helped others by having valued roles; (d) make choices and have control of their lives; and (e) improved skills and abilities in their strengths and interest areas (O'Brien & O'Brien, 1998). The AAIDD (2010) recommends that planning teams work together using a five-step process to assess, develop, plan,



and deliver supports through a person-centered process.

- Step 1. Identify desired life experiences and goals.
- Step 2. Determine the pattern and intensity of support needs
- Step 3. Develop an individualized plan
- Step 4. Monitor the progress.
- Step 5. Evaluate.

Information from this process should be used to create age-appropriate supports and services. Information about age appropriate supports and services is discussed in module 3.

As a DSP, you may be asked by an individual with a disability to participate in their PCP meeting. Therefore, we want you to be familiar with the meeting process. PCP requires a facilitator (leader) using a PCP framework or method to lead the planning meeting. Most PCP methods include (a) creating a vision for the future (Where do I want to be in 5 years? What do I want to be doing in 5 years? Where do I want to be working in 5 years?); (b) identifying the person's strengths and interests (What am I good at? What do I like doing?); (c) identifying the person's support needs and preferences (What do I need help with? Who do I like helping me? What do I like doing best?); (d) identifying needed resources and/or skills to achieve the goals (What do I need to learn?); (e) identifying short-term goals which are focused on the vision (What can I do today to help me get the job I want?); (f) developing an action plan to achieve the short-term goals (Taylor & Taylor, 2013; O'Brien & O'Brien, 2003).

Charting the LifeCourse framework has been adopted statewide by the Utah Department of Human Services, Division of Services for People with Disabilities (<https://dspd.utah.gov/resources/person-centered-planning/>).

The Charting the LifeCourse (CtLC) framework was created to help individuals and families of all abilities and all ages develop a vision for life, think about what they need to know and do, identify how to find or develop supports, and discover what it takes to live the lives they want to live. CtLC includes planning for eight areas: daily life and employment; community living; social and spirituality; healthy living; safety and security; advocacy and engagement; supports for family; and supports and services.

There are multiple Charting the LifeCourse tools which may be used to lead



a PCP meeting. To learn more about each of these tools review the linked videos.

- [*Tool for Developing a Vision*](#): The tool helps the individual and the PCP in developing a shared vision with the individual in the 8 areas. The outcome of this tool is setting long-range goal for the individual to develop an improved quality of life in all life areas.
- [*Life Trajectory Worksheet*](#): This tool helps the individual to create a vision for the future based on their preferences and past experiences. This tool helps the individual and PCP team to figure out what they want based on their preferences as well as things to avoid based on their past negative experiences. This tool results in a visual which shows a long-term goal of what a person wants, as well as what they don't want, in their lives.
- [*Integrated Supports Star*](#): This tool leads a discussion with the individual and their team for a holistic (whole life) analysis of the support available.
- [*The Relationship Map*](#) : This tool leads a conversation to identify people who are in the individual's life. This tool can identify areas where relationships are and are not in the person's life and need to be explored.
- [*Tool for Exploring Decision-Making Supports*](#): The tool helps individuals and PCP team explore the level of support needed in making decisions for each area.
- [*Integrated Long-term Support Needs Tool*](#): This tool is used to visualize a daily schedule of the supports an individual currently receives, figure out needed where supports may be needed.

Reflection Questions

- In what ways are you supporting a person to have relationships with friends & family?
- In what ways do the people you support show their preferences?
- What opportunities do the people you support have to learn & practice independence?
- How are you listening and acknowledging people's choices?

Informed Choice



Without real-life experiences, the person with a disability will be unable to make an informed choice about their strengths, interests, and preferences.

All individuals are given more freedom and choice as they grow up. Youth are guided by parents, guardians, teachers, support professionals as they go to school, daily living skills, and be active in their towns. As a child becomes a teenager, more and more choices for independence are given to the individual. By the time and they start middle school and high school (14–21-year-old), teenagers are encouraged to make choices and make decisions about their employment, training, independent living (where they live) and community participation (where they go and what they do in their town). Unfortunately, youth with I/DD may have limited experiences in life to explore and learn about the different careers, training, housing, and community activities (Wehman et al., 2019). Many people with significant disabilities are not always given opportunities to make informed choices (Neely-Barnes et al., 2008). Why aren't youth with disabilities given chances to learn about being an adult? First, people may think the youth with a disability is not able to make informed choice. Second, an individual may lack experiences in school, home, and community (town/city). Because they don't have real-life experiences, the person with a disability won't be able to make an informed choices about their strengths, interests and preferences (Curryer et al., 2015). For example, a transition-age youth has only worked in the laundry sorting clothing by color. When asked what type of a job they would like in the future, they are more likely to say the only job they know – working in a laundry. However, if this youth had the chance to perform many jobs in different businesses, they might want a different job.

Concerns about Health Care

Parents and family members of people with disabilities are frequently worried about decision making about healthcare.

[Supported Decision Making](#) video gives examples of individuals making supported-decisions related to their healthcare.

By giving many opportunities to explore jobs, community events (festivals, clubs, dances), and recreational activities (swimming, biking, hiking, skate boarding, skiing, etc.), youth and young adults with I/DD are able to make an informed choice of their preference of daily activities and community-based activities.



Research on Transition to Work

Research suggests that transition-age youth who have more work experiences or jobs before exiting high school are four times more likely have a paid job as an adult (Mazzotti et al., 2021).

There are evidence-based lesson plan starters for teaching decision making skills for youth with I/DD (for example, [Using Self-Monitoring to Teach Decision Making for Leisure Activities](#)). For youth who are non-verbal, a choice board of pictures of activities given to them may be used to point/eye gaze and pick the preferred activity. The first step in decision-making instruction is to assess the youth's current level of decision making. One assessment tool, *Stop, Look, and Listen: Planning for Independence and Adult Decision-Making Support*, can be used with any age of youth to develop a baseline of their opportunity for making decisions in their lives.

Activity

Download [Stop, Look, and Listen](#) and complete it for a youth that you support at the ICF/ID. After completing the assessment and reading through the opportunities to develop independence and practice decision making, ask yourself how you can integrate this tool into a youth's programming and supports every day.

Supported Decision Making

Parent(s) or guardian(s) must be included in all decisions about youth who have not reached the age of majority. Once a youth reaches the age of majority (age 18 as established by Utah Code 15-2-1), the youth becomes an emancipated adult. An emancipated adult means the person has the legal right and responsibility to make all education, housing, healthcare, financial, legal, and daily decisions in their life. Some people will require additional support in order to learn and practice decision-making skills (Werner, 2012). Supported decision-making (SDM) ensures people can make their own decisions and have personal control of their lives, while receiving the support and guidance they need to make informed choices. SDM empowers people with disabilities to use a combination of supports from family members, friends, trusted community members and professionals to provide supports and guidance for decision making (Dinerstein, 2012). Through



SDM, people with disabilities can be independent with the least restrictive support. Research has shown that youth independence and decision making is a predictor to post-school success (Mazzotti et al., 2021).

[The National Resource Center for Supported Decision Making](#) has identified the following process for an individual with a disability to consider when establishing a support relationship:

- Think about the type of decisions the person you support needs help making and the type/amount of help needed.
- Talk to people who can help and discuss what type of help is needed and when.
- Then, when the person needs to make a decision and needs help to understand it, the person and supporter get together so the person can get the help and make the decision.
- Create a written plan saying the people who will provide support, when they will provide it, and how. The person with a disability may want to share that plan with others. For example, if the individual wants their sister's support making medical decisions, a written plan between the person and their sister would outline that support. Then, the plan would be shared with the doctor, so the doctor recognizes the sister as part of the person's health care team.

Guardianship and Least Restrictive Alternatives

Guardianship decisions are based on the assessment of the capacity of an individual. Under Utah code, capacity or incapacity is measured by functional limitations and means a judge decides after proof by clear evidence that an lacks the ability, even with appropriate technological assistance, to meet the essential requirements for financial protection or physical health, safety, or self-care and (a) receive and evaluate information, (b) make and communicate decisions, and (c) provide for necessities such as food, shelter, clothing, health care, and safety (Utah Uniform Probate Code 75-1-110). A court petition for guardianship must include a written report/evaluation that was performed by a physician or psychologist. The report must provide a comprehensive assessment of any functional impairments and a description of how these impairments impacted a person's capacity. In



aligning with the QOL standards previously discussed, a guardianship should serve as an advocate for an individual with I/DD to be more actively involved in the decision-making process.

When addressing healthcare needs, the National Guardianship Associations (NGA) states that the person's participation in the decision-making process should be maximized. The guardian should learn all of the medical facts about the person with I/DD and understand the health care options and the risks/benefits of each option. After the guardian educates themselves, it is important they encourage and assist the individual with I/DD to learn the same facts about the health care options. Based on that knowledge, the individual with I/DD should be supported to direct the decision (National Guardianship Association, 2013, p.15).

Although an adult with I/DD may have a guardian appointed by the court, the guardian should continue supporting the self-determination and independence of the person with I/DD. Any decisions that are made should have the input and direction of the individual with I/DD. The guardian should also ensure that all decisions respect the individual's rights and be provided in the least restrictive environment (National Guardianship Association, 2013, pp. 8-9).





National Guardianship Associations (NGA) Standards for Decision Making

The guardian shall identify and advocate for the person's goals, needs, and preferences. Goals are what are important to the person under guardianship, whereas preferences are specific expressions of choice.

First, the guardian shall ask the person what they want.

Second, if the person has difficulty expressing what they want, the guardian shall do everything possible to help the person express their goals, needs, and preferences.

Third, only when the person, even with assistance, cannot express their goals and preferences, shall the guardian seek input from others familiar with the person to determine what the individual would have wanted.

Finally, only when the person's goals and preferences cannot be determined, may the guardian decide in the person's best interest (National Guardianship Association, 2013, pp. 7-8).

Implications for Youth Under Age 18

DSPs can support youth under age 18 to build functional capacity to make informed decisions. Functional capacity skills are particularly important because petitions for guardianship appointments are often made with the intention of protecting the safety and well-being of an individual with I/DD. The court uses information submitted to the court about an individual's capacity and functional limitations. Unfortunately, the tests used to determine the capacity of individuals with I/DD are typically

standardized assessments such as intelligence (IQ) test and behavior scales (Millar & Renzaglia, 2002). These tests do not accurately address the functional skills needed to



make independent living choices. Further, there seems to be little planning at the middle school and high school level to prepare and support youth and young adults to make important decision (Payne-Christiansen & Sitlington, 2008). The middle school and high school transition years are critical time to teach the functional skills need to make informed decisions. There are multiple assessments (i.e. Guardian Alternative Model, Guardian Alternative Assessment Template, Supported Decision Making Personal Factors Inventory) available for



professionals to guide individuals, parents, family members to figure out the level of support needed for decision-making (Oertle & Riesen, 2019). For example, the Guardian Alternatives Assessment Template (GAAT) developed by Millar (2014), is designed to ensure youth with I/DD explore alternatives to guardianship and to develop the skills that are aligned with self-sufficiency.

The GAAT helps individuals with I/DD and their family identify a vision, identify values, and identify preferences. The GAAT has several sections that examine:

- **Daily living**
 - Independent living, money, transportation, social skills, vocational skills.
- **Cognitive functioning**
 - Problem solving, executive functioning, communication.
- **Risk of harm and least restrictive guardianship alternatives**
 - Consent for medical treatment, money management.
- **Opportunities to enhance capacity**

The GAAT and other assessment strategies reinforce the need to look for least restrictive alternatives to guardianship and prepare individuals for the demands of adult living. Table 4.1 provides a summary of the most common least restrictive alternatives.

Table 4.1
Summary of Least Restrictive Alternatives

Summary of Least Restrictive Alternatives	
Alternative	Description
<i>Advanced health care directives</i>	Oral and written instructions about future medical care should the individual become unable to make decisions (for example, unconscious or too ill to communicate). Each state regulates the use of advance directives differently. A living will is one type of advance directive. It takes effect when the patient is terminally ill. An advanced health care directive can be part of a living will.
<i>Health care power of attorney</i>	A health care power of attorney lists who is assigned to make health care related decisions on an individual's behalf. The



	document includes the agent's powers and limitations, guidance on the preferences and wishes of the individual (including end-of-life care), and when the document will become effective.
<i>Financial representative payee</i>	A representative payee is for Social Security Income. It allows another person or agency to manage another person's income. The payee will need to keep good records in case there is an audit to show how the money is spent to pay the personal living expenses the person with a disability.
<i>Credit limits and prepaid credit cards</i>	Credit limits and prepaid credit cards can be option for individuals who may have difficulty keeping track of credit limits or finances
<i>Special needs trusts</i>	Trusts are legal arrangements between an individual and another person (or institution) called a trustee. The trustee manages the adult's assets (money and what they own) including their money and property. Upon the death of the person with a disability, any money left over will go to the beneficiary of the trust.
<i>Durable power of attorney</i>	A financial power of attorney is a document designating another person to manage and assist the individual with finances. A durable power of attorney becomes effective immediately upon signing the document.

Module Summary

This module provided an introduction to person-centered planning and the foundation it gives to facilitate informed choice and supported-decision making related to independent living, competitive integrated employment, inclusive social and recreational activities. This module provided information on ways in which people with disabilities can make informed choice through supported decision making. Finally, this module addressed the various types of guardians and gives guidance for guardians to promote the individual's rights and self-determination in the least restrictive environments.



Key Takeaways

- PCP focuses on the person's strengths, interests, preferences, support needs to develop goals with the person.
- Youth independence and decision making is a predictor to post-school success.
- At the age of 18, all individuals become emancipated adults regardless of disability.
- Supported decision making allows people with disabilities to make informed choices and maintain their rights and independence.
- The guardian's role is to advocate for the person's goals, needs, and preferences in the least restrictive environment.



Module 5: Collaboration and Transition from Secondary School to Adulthood





This module gives information about how to successfully collaborate with parents, guardians, and adult service providers to support transition-age youth with I/DD obtain meaningful adult outcomes. The module identifies ways a DSP may collaborate with secondary special educators to develop transition individualized education programs (transition IEPs) for successful postsecondary outcomes. The module will also review how to work with adult service providers, such as vocational rehabilitation counselors and adult service agencies, to work toward community inclusion and competitive integrated employment goal.

At the conclusion of this module, you will be able to:

- Understand the roles and responsibilities of parents and transition stakeholders in the transition process.
 - Understand effective communication and collaboration strategies with parents
 - Know the impact of age of majority on planning meetings and services
 - Know the essential elements of effective collaboration
- Understand the purpose of the transition IEP and its components.
 - Know the predictors for successful postsecondary outcomes
 - Able to read and understand the sections of the transition IEP
 - Learn what information to exchange daily with school contact
- Identify ways to contribute to the successful transition for youth into inclusive community living, participation and competitive integrated work.

The following table lists key terms you will need to know for Module 5.

Term	Definition
<i>Collaborate</i>	To work jointly with others to complete a task or goal.
<i>Secondary education</i>	Education from grade 6 to 12.
<i>Postsecondary</i>	Education following secondary education.; typically done from age 18 to 21.
<i>Community inclusion</i>	Inclusion in the community through employment, leisure and recreational activities, and/or health services.
<i>Competitive integrated</i>	Employment that is paid at least at minimum wage and is commensurate with other employees doing similar work



<i>employment</i>	and is done in the general community with coworkers who may or may not have a disability.
<i>Independent living</i>	Having opportunities, skills, services, and adaptive equipment if necessary to live on one's own in their home or community.

Introduction to Special Education Transition

In this context, transition describes the process of moving from secondary education to adult life. For youth with disabilities, the Individuals with Disabilities Education Improvement Act (IDEA, 2004) requires that secondary education prepare for life after high school by writing and following a transition individualized education program (IEP) at the age of 16. In Utah, the transition IEP is required to be written and followed when a youth turns 14 years old (Utah State Board of Education, Special Education Rules, 2020). IDEA (2004) specifies that the transition IEP must include transition services which are a coordinated set of activities that are (a) designed to be within a results-oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child's movement from school to post-school activities, including postsecondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation; (b) based on the individual child's needs, taking into account the child's strengths, preferences, and interests; and (c) includes, instruction, related services, community experiences, employment and other post-school objectives, and daily living skills.

Alone we can do so little; together we can do so much.

~Helen Keller

To prepare youth for successful adult outcomes, researchers identified secondary instruction, activities, and experiences which are predictors of postsecondary success (Mazzotti et al., 2021). These predictors are practices of youth behaviors that increase the likelihood of the youth with a disability obtaining valued post-school outcomes. Although as a DSP, you will not be in a position to address and support all of these areas, you should know there are areas that could



be prioritized on their individual plans to develop skills outside of their classroom instruction. For example, possessing self-care skills and independent living skills, and developing social skills are within the scope of daily activities outside of the classroom room. Module 6 addresses instructional strategies which you would use to teach these skills. It is essential for transition-age youth that you offer support to an individual to learn the task, rather than doing the task for the youth. The National Technical Assistance Transition Center (NTACT) has [evidence-based lesson plan starters](#) which can be used as instructional guides for evidence-based teaching methods for many of these skills.

Evidence-Based Predictors

- Career and Technical Education
- Exit exam/high school diploma
- Inclusion in the general education curriculum,
- Paid employment/work experiences
- Parent expectations
- Psychological empowerment
- Program of study
- Self-care/independent living skills
- Self-determination/self-advocacy
- Self-realization
- Social skills
- Youth support
- Work-study

Because all students with disabilities between the age of 3-21 are entitled to a free appropriate public education (FAPE, see module 1), the public school system has been the single provider of education, job training, employment supports, therapies, and community-based instruction for youth with disabilities. However, when a youth exits secondary education by graduating or aging-out of special education services at 21 years of age, those services end. As youth prepare to exit secondary education, there is a shift from entitlement to eligibility for services. In order to receive ongoing services, the transition-age youth must be found eligible for services. Further complicating the process, each agency has its own application and eligibility process. There is not a single funding source or a single agency that will fund and provide the broad range of services that were provided by the school. For many youth and families, this becomes a confusing



process which requires support, guidance, and interagency collaboration with the transition-age youth's case conference committee members, agency representatives, provider agency representatives, and agency staff. Many researchers (e.g. Kohler et al., 2016; Noonan et al., 2008; Oertle & Trach, 2007; Test et al., 2009; Wehman et al., 2014) reference interagency collaboration as a promising practice in the transition process.

Collaboration is defined as “direct interaction between at least two coequal parties voluntarily engaged in shared decision making as they work toward a common goal (Friend & Cook, 2017).” Collaboration allows for youth, parents, educators, and adult agency representatives to learn from each other and develop a unified plan for assisting the youth to transition successfully to adulthood. For interagency collaboration to be effective, all of the partners must be familiar with each person and/or agency's role and responsibilities (Friend & Cook, 2017). In the following section, the roles and responsibilities of interagency collaboration are highlighted.

The youth should always be included in meetings about their education, healthcare, and services. As part of the transition process, youth should join in the PCP process and community-based activities to identify their strengths, interests, preferences, and needs. Completing functional assessments and age-appropriate transition assessments help to identify and refine postsecondary goals for employment, education/training, and independent living.

Parents are the experts on their children. A parent/guardian's role is to advocate for a quality of life for their child with a disability. They will give critical information about their children's strengths, interests, preferences, and support needs as part of the person-centered planning process and case conferences. When their child is a minor (<18 years), they will also be responsible for applying for resources in their child's name such as Supplemental Security Income (SSI), Medicaid Insurance, Medicaid Eligibility, and Vocational Rehabilitation (VR) Services. Parents may also support their child to register for a training with a Center for Independent Living, purchase a public transportation pass, and obtain a state identification card. (See Table 5.1 for a summary of these community resources.) As discussed in Module 4 when a youth with a disability reaches the age of 18, they become an emancipated adult and are legally responsible for making their own decisions (Utah Code 15-2-1). As a legal adult, the transition-age youth with a disability must agree their parent/guardian may attend their meetings, case conferences, doctor appointments, and agency appointment.



Table 5.1
Community Resource Summary

Community Resource	Information
Social Security Administration	Ssa.gov Benefits for Children with Disabilities: https://www.ssa.gov/pubs/EN-05-10026.pdf What You Need to Know about SSI When You Turn 18 https://www.ssa.gov/pubs/EN-05-11005.pdf
Medicaid Benefits	Medicaid is a state/federal program that pays for medical services for low-income pregnant women, children, individuals who are elderly or have a disability, parents and women with breast or cervical cancer. To qualify, these individuals must meet income and other eligibility requirements. https://medicaid.utah.gov/apply-medicaid/
Medicaid Home & Community Based Services (HCBS) Waivers	Utah waiver programs that provide home and community-based services to a limited, targeted group of individuals whose cost to live in the community has to be the same or less than if they lived in a nursing facility. Individuals may participate in a waiver only if they require the level of care provided in a hospital nursing facility (NF) or an intermediate care facility for people with intellectual disabilities (ICF/ID). If a youth is selected for a waiver, they may choose to leave the ICF/ID and move into a community setting with waiver supports. Utah Has Eight Medicaid 1915(c) HCBS Waivers: <ul style="list-style-type: none">• Acquired Brain Injury Waiver• Aging Waiver (For Individuals Age 65 or Older)• Community Supports Waiver for Individuals with Intellectual Disabilities or Other Related Conditions• Autism Waiver• Medically Complex Children’s Waiver• New Choices Waiver• Physical Disabilities Waiver• Technology Dependent Children



<u>Utah Disability Care Services</u>	<ul style="list-style-type: none">• For more information click https://medicaid.utah.gov/ltc/ Intermediate Care Facility Services for Individuals with Intellectual Disabilities (ICF/ID) provide twenty-four-hour residential supports for people with developmental disabilities. They are a part of the continuum of care for people with special needs in our communities. ICFs/ID specialize in caring for people with intellectual disabilities with the goal to assist each individual to become as independent as possible. Ranging in age from children to elderly, each resident is taught life skills and receives additional training, encouraging them to reach their highest potential. For more information click https://disabilityservicesutah.org
Utah Office of Vocational Rehabilitation (USOR)	A mandate partner in the transition process with secondary special education. USOR supports eligible individuals with disabilities in obtaining and maintaining competitive, integrated employment through professional vocational counseling and guidance, and through partnerships with employers, school districts, higher education and other agencies. https://jobs.utah.gov/usor/vr/index.html
<u>Division of Services for People with Disabilities</u> (DSPD)	The Division of Services for People with Disabilities (DSPD) gives supports for people with disabilities to lead self-determined lives by overseeing home and community-based services. Support includes community living, day services, and supported-employment services. https://dspd.utah.gov/
<u>Utah Center for Assistive Technology</u> (UCAT)	The Utah Center for Assistive Technology (UCAT) is a statewide resource offering information and technical services to help people with disabilities acquire and use assistive technology devices. UCAT offers free evaluations to anyone within the state of Utah. https://jobs.utah.gov/usor/vr/services/ucat.html
<u>Utah Independent Living Center</u> (UILC)	The mission of the Utah Independent Living Center (UILC) is to assist persons with disabilities achieve greater independence by providing services and activities which enhance independent living skills and promote the public's understanding, accommodation, and acceptance of their



	rights, needs and abilities. Services focus on independent living skills, advocacy, peer support, information and referral and transition. https://uilc.org/en/
<u>Utah Parent Center</u>	The mission of the Utah Parent Center (UPC or Center) is to help parents help their children, youth, and young adults with all disabilities to live included, productive lives as members of the community. We accomplish our mission by providing accurate information, empathetic peer support, valuable training and effective advocacy based on the concept of parents helping parents. https://utahparentcenter.org

Vocational Rehabilitation

The Vocational Rehabilitation Counselor’s (VRC) role is to provide guidance, career counseling, and information about competitive integrated employment and the training and support required. The VRC may contribute to the development of the postsecondary goal for employment in the transition IEP. In addition, the VRC may have recommendations for transition services and activities that would be beneficial to the youth to complete during high school as they develop and acquire skills to obtain their career goal. One of the services that may be recommended is Pre-employment transition services (Pre-ETS) which are funded by VR. Pre-ETS are offered to any youth with a disability (see Module 1) and supports youth in exploring and planning for successful future employment, through targeted training (<https://jobs.utah.gov/usor/vr/services/youth/preemploy.html>). Prior to exiting high school, the transition-age youth should apply to VR; the VRC determines the eligibility for the VR services; if found eligible, the VRC will develop an Individualized Plan for Employment (IPE) to support the transition-age youth to obtain their career goal. There are a number of employment services offered by Utah VR.

Supported employment. SE gives support to find and maintain employment. Often the job seeker will work with a community rehabilitation provider (CRP) to find and maintain the job through job development, job placement and job coaching services provided by the CRP, but paid for by OVR.



Customized employment (CE). CE is designed for people with more significant disabilities. CE explores and identifies the employment seeker's skills interests, and needs through a discover process. Job content, tasks and environment are tailored to the employment seeker's skills and interests in a process of negotiation and collaboration between the client, the CRP, and the employer.

Individual job placement and support (IPS). IPS an evidence-based supported employment model to assist individuals with a primary or secondary diagnosis of mental illness in finding employment that meets their specific needs, interest and skills, and supports them in ways that promote success in the workplace (<https://jobs.utah.gov/usor/vr/services/work.html>)

Communication to Improve the Transition Process

In addition to providing opportunities for transition-age youth to learn and practice the skills which are predictors to postsecondary success, there are other practical ways for you to help in the transition process. The following shows ways the DSP can use to collaborate with the secondary education staff.

Daily Communication Exchange

Through an agreed upon method, provide the teacher with daily communication about the youth. This is especially important if the youth is non-verbal and cannot share specific joys or frustrations with the teacher. Ongoing communication will assist the teacher with appropriate support for the youth in the classroom. For example, the communication can let the teacher know if the youth is going home for the weekend and excited to see their parent or if the student experienced situations that might impact the student at school (e.g. an argument with a roommate). This type of information can help a teacher be proactive in their approach and programming with the student for that day. Other information to communicate to the teacher might include: medicine changes/medical issues, food intake, physical injury, or toileting needs. DSPs should talk to the teacher to determine what type of communication is preferred in certain situations (e.g. email, text, written notes, phone call). For example, there may be times a text that is read immediately is needed. Other times the communication could be an email that could be read before the youth arrives at school. Others may prefer a written journal to travel back and forth daily with the youth.






Practicing Scripts

A speech language pathologist (SLP) may develop a script for youth to practice greeting people or other social communication. Using a script is an evidence-based practice where a verbal or written description of a conversation that a youth would encounter. By practicing scripts, the youth practices speaking for themselves. The staff should ensure that that the youth is answering questions and speaking for themselves. Staff should not speak for the person with a disability, instead they should wait for the individual to respond. The script acts as a model for the learner and should be practiced repeatedly for the youth to learn the skill (Wong et al., 2015). See examples of sample scripts in Figure 5.1.

Figure 5.1

Example Practicing Script

A youth is going ice skating with his friends from the YMCA.
A script could be practicing requesting a pair of skates.

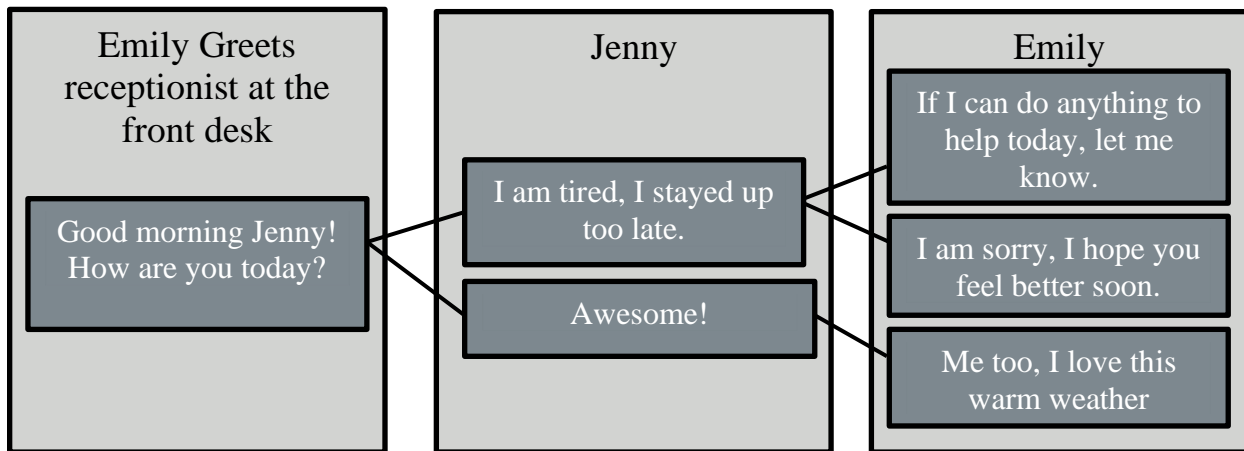
	<p>“Hi, May I have a pair of size 8 skates please?”</p> <p>“Hi, May I have a pair of size 8 skates please?”</p>
	<p>The rink employee would find the correct skate and hand to the youth</p>
	<p>“Thank you.”</p> <p>“Thank you.”</p>

A script may be used to practice different responses to conversations. For example, if a youth is learning how to greet co-workers at their work experience at Intermountain Healthcare, they would have to know how to respond to positive and negative comments. See Figure 5.2 below as an example.

Figure 5.2



Example Practice Script



Using Consistent Visual/Picture Prompt or Communication

The teacher may use Picture Exchange Communication System (PECS) in the classroom to communicate with the youth or use visual schedules to prompt the youth throughout the day. Working with the teacher to implement this consistent communication tool throughout a youth's day will benefit the youth to perform tasks independently. For example, developing a visual schedule for getting dressed in the morning or preparing a simple meal or snack.

Portfolio Development

Supporting the youth to create a personal portfolio is a positive way for a youth to share their personal strengths, interests, preferences and needs. The youth would pick items to include and could use it as an introduction during their transition IEP meeting or when they are meeting with adult service providers.

As this module shows, preparing a youth to transition from secondary education to adulthood is a complex process. Each person and agency has an important role and responsibilities which will contribute to the young person achieving a meaningful life.

Module Summary

This module gave information about how to successfully collaborate with



parents, guardians, and adult service providers to support the transition from secondary education to adulthood. The module showed ways a DSP may collaborate with secondary special educators to develop transition individual education programs (transition IEPs) for successful postsecondary outcomes. The module reviewed the roles and responsibilities of the youth, parent and community transition agencies in the transition process to work toward community inclusion and competitive integrated employment goals.

Key Takeaways

- Interagency collaboration is needed for successful transition from school to adulthood.
- Evidence-based predictors should be taught during high school to prepare the youth for a successful transition to adulthood.
- There are multiple ways a DSP can assist a youth to prepare for independence during daily activities.

Reflection Questions

- Do you support the transition-age youth you work with to perform tasks independently or do you do tasks for them because you can do it faster?
- Have you practiced communication scripts with the transition-age youth you work with or do you talk for them?



Module 6: Independent Living Instruction





Module 6 gives information about how to identify training areas for independent residential and community skills such as self-care, meal preparation, laundry, transportation, social and soft-skills, recreation and leisure, and employment skills. The module will explore how DSPs can develop appropriate instructional programs and use systematic instruction to teach individuals with disabilities the acquisition of these critical skills.

At the conclusion of the module, you will be able to:

- Describe the importance of teaching independent living skill and community skills instruction to individuals with I/DD.
- Describe how to determine what skills to teach.
- Describe how to conduct an ecological inventory.
- Describe how to develop and use a task analysis.
- Describe how to use response prompting and fading procedures.
- Describe how to collect and summarize instructional data.

The following table lists key terms you will need to know for Module 6.

Term	Definition
<i>Systematic instruction</i>	A planned-out sequence of instruction in order to teach a learner a new skill.
<i>Ecological inventories</i>	A list of demands of specific environments and skills necessary to participate in these environments.
<i>Task analysis</i>	A process of breaking down a task into smaller, teachable steps.
<i>Non-controlling prompt</i>	A prompt that will increase the likelihood of a learner's response.
<i>Controlling prompt</i>	A prompt that will reliably and consistently elicit a correct response from the learner.
<i>Hierarchy of prompts</i>	Prompts that are sequenced in a particular order, such as least to most.
<i>Compensatory</i>	Strategies for supporting an individual that may include modifications or additional equipment to complete a task.



The Importance of Individualized Instruction

DSPs must understand how to teach and prepare individuals with I/DD to independently engage in multiple living and community domains. The notion of independence is directly correlated to improved QOL. That is, when a person can independently complete a task and can engage in meaningful community environments, that person overall QOL improves (Shalock et al., 2005).



Meaningful community integration and participation also increases choice and self-determination, improved employment, improved family contact, and improved social skills. In addition, meaningful community integration also improves adaptive skills and challenging behaviors of persons with I/DD (Larson et al 2013).

It is important to highlight that learning opportunities must be directly connected to the strengths and interests of an individual and be aligned with that person's direct needs. Independent living and community skills should be taught after support staff conduct thorough and consistent assessments to determine what skills will maximize and facilitate independence and community participation. Without proper planning and systematic instruction, many individuals with I/DD will not develop their full potential for successful community living.

Improving Adaptive Behaviors

Researchers conducted a review of associations between moving from institutions with 16 or more residents to smaller community settings and adaptive behaviors (Larson et al., 2013). The researchers found highly consistent evidence that people who live and engage in the community have improved adaptive skills such as language/communication, social skills, motor skills, and vocational skills.



Teaching Independent Living Skills

Determining what skills to teach is critical component of instructional planning. Each skill should enhance a person with I/DD's quality of life in regard to physical well-being, material well-being, social well-being, productive well-being, emotional well-being, and civic well-being and be taught in meaningful residential, community living, employment, and recreation environments. The skills may also be identified as a priority during the person-centered planning process. DSPs should address an individual's needs, the types of supports available, the modifications and adaptations, and the skills that need to be taught in a number of domains including, domestic, personal care, health and safety, money management, home maintenance, food management, time management, morning, day, and evening routines, and leisure (Storey & Miner, 2011).



Considerations for Teaching Independent and Community Skills (Sailor et al., 1988)

1. The skill that is taught has immediate utility for the person.
2. The skill is desirable for the person.
3. The skill is acquired in a social context – acquisition is the product of interactions with more than one care giver.
4. The skill is acquired in the actual, physical environment where the skill is naturally performed.
5. The skill is age-appropriate.
6. The skill is adaptable.

Using Ecological Inventory to Determine Skills to Teach

Ecological inventories are used to analyze the demands of specific natural environments and to determine relevant skills needed to engage in these environments. According to Storey and Miner (2011), there are a number of steps to conducting an ecological inventory.



Step 1

Determine whether the skill or task occurs in a residential and community domain. These domains should be socially valid and relevant for the individual with a disability. For example, cleaning the floorboards on a daily basis is not relevant to day-to-day living. Learning to wash and fold clothing, however is relevant to day-to-day living.

Step 2

Identify the current and future natural environments where instruction is necessary. This is important because we know that teaching people with I/DD in the environments where they are expected to perform is critical to maintaining a skill (i.e. Vocational tasks should be taught in applied/real life work settings).

Step 3

Identify the sub environments within larger environments. For example, if you were exploring domestic skills, the environment would be the residential setting and the sub-environments where a skill or activity occurs such as the bathroom, kitchen, bedroom, etc.

Step 4

The fourth step is to identify the activities that occur within the sub-environment. Using the bathroom example, the DSP would document activities that occur in a bathroom such as washing hands, brushing teeth, and using the restroom.

Step 5

Identify the skills that are necessary to meaningfully engage in the activity. For brushing teeth, the individual would need to turn sink water on, unscrew toothpaste, apply toothpaste, brush teeth, rinse.

Example Ecological Inventory

We provided two examples of ecological inventories. One example is an inventory for a residential setting/restroom and the other is for a community setting. When completing an ecological inventory, it is important to observe other individuals performing each activity to determine the requisite skills. After



observing others complete the activity, observe the person with I/DD complete the skill and document whether the person completed the skill correctly or incorrectly and document the type of instructional support the person will need. The type of instruction support can include teaching the skill or adapting/modifying the skill.

Figure 6.1

Example Ecological Inventory for Grooming

Ecological Inventory			
Personal Care and Hygiene/Grooming			
Name: Eddy Vedder			
Environmental Setting: Residential			
Sub-Environment: Bathroom			
Skill	Performance Level		Notes
	Independent	Needs Support	
Washing Hands		X	Eddy does not thoroughly wash his hands. He briefly places them in water, uses no soap, and does not sufficiently scrub hands. This skill needs to be taught.
Brushing Teeth		X	Eddy does not thoroughly brush his teeth. He only briefly brushes each side. Possible adaptation is a sonic care tooth brush. This skill needs to be taught.

Figure 6.2 is an example of an ecological inventory for using an ATM in the community. In this example, the DSP observes an individual making a deposit and withdrawing cash at an ATM. The DSP documents the performance of the individual by recording if they correctly or incorrectly perform the task. The DSP then indicates what type of instruction support is needed to deposit or withdraw money. In this example, the DSP decides that the individual needs instruction and support on both skills.



Figure 6.2
Example Ecological Inventory for Community Setting

Ecological Inventory			
Banking			
Name: Eddy Vedder			
Environmental Setting: Key Bank			
Sub-Environment: Outdoor ATM			
Skill	Performance Level		Notes
	Independent	Needs Support	
Using an ATM for deposit	X		He knows his pin number and can enter his debit card into the machine. Eddy has trouble selecting the correct buttons on the ATM screen.
Using an ATM for a Withdrawal	X		

Task Analysis

After conducting an ecological inventory to document what type of instructional support is needed to learn the targeted skill, the DSP should develop a plan and corresponding instructional programs to teach identified skills. TA's are useful because they help identify every discrete behavior needed to accomplish a specific activity or task. The most effective method for developing a comprehensive task analysis is to personally complete each step of the task. In addition, the DSP should develop a clear definition of the activity or skill that the individual is expected to perform in observable and measurable language. Figures 6.3 and 6.4 are examples of a TA for a residential and community-based skill.



The first step to teaching is to develop a task analysis (TA). A TA is a process of breaking a task down into smaller teachable steps.



Figure 6.3

TA for Hygiene/Brushing Teeth

TA Brushing Teeth		
Observable and Measurable objective: Given a toothbrush and toothpaste, Jerry will independently brush teeth with 100% accuracy for 3 consecutive trials according to the steps outlined in the task analysis.		
Setting: Bathroom		
Materials: Toothbrush, toothpaste, sink, and running water		
Step	Quality and Speed	Comments
Pick up the toothbrush		
Wet the brush		
Remove cap of toothpaste		
Put paste on the brush		
Brush the top teeth on the right side		
Brush the bottom teeth on the right side		
Brush the top teeth on the left side		
Brush the bottom teeth on the left side		
Brush the top front teeth		
Brush the bottom front teeth		
Rinse brush		
Spit in sink		
Put brush in holder		
Rinse mouth with water		

Figure 6.4

Using an ATM

TA for Withdrawing Money from an ATM



Observable and Measurable objective: Given a debit card and an ATM machine, Jerry will independently withdraw \$20.00 from an ATM 100% accuracy for 3 consecutive trials according to the steps outlined in the task analysis.

Setting: ATM at KEYBank

Materials: Debit card

Step	Quality and Speed	Comments
Insert debit card into ATM		
Enter four-digit PIN 6383		
Press enter		
Select withdraw		
Select checking account		
Select at push button for \$20.00		
Press button to confirm withdrawal		
Select exit/print receipt		
Remove card		
Remove cash		
Remove receipt		

Instructional Strategies

DSPs should be familiar with an array of strategies that can be used to teach the acquisition and maintenance of residential, community, and vocational tasks. Professionals use response prompts to increase the probability of correct responses (Wolery et al., 1988).

Table 6.1
Types of Response Prompts



Response Prompt	Description
Indirect Verbal Prompt	An indirect verbal prompt is an indirect verbal statement that cues a individual about an expected response. For example: “What do you need to do now?” or “What is next?”
Direct Verbal Prompts	A direct verbal prompt explicitly cues the individual about the expected response. For example, “Put the toothpaste on your toothbrush.”
Gesture Prompts	Nonverbal instructor prompts or gestures that draw attention to the stimulus material such as pointing at the correct button on the ATM. Screen.
Model	The DSP models and demonstrates how to perform the expected response.
Physical Assistance	An DSP may use a full physical prompt such as hand-over-hand prompting to guide the individual to a correct response. A DSP may use a partial physical prompt, such as touching a hand or an elbow. For example, the DSP might tap the individual on the elbow to cue him/her pick-up the toothpaste.

Prompts are typically categorized from the least intrusive to the most intrusive and may include indirect verbal prompts, direct verbal prompts, gestures, model prompts, and physical prompts (Table 6.1).

According to Wolery et al. (1988), there are six primary guidelines for using response prompts. In order to maximize the effectiveness of an instructional program and increase the effectiveness of the response prompt it is recommended that these guidelines be followed:

- **Select the least intrusive but effective prompt.** The instructor should use the least intrusive prompt that effectively elicits the correct target behavior from the student. That is, the instructor should allow the student to perform the target behavior as independently as possible.



- **Combine prompts if necessary.** If necessary, instructors can combine or blend prompts to increase instructional effectiveness. For example, the instructor can blend a model prompt with a direct verbal prompt.
- **Select natural prompts and those related to the behavior.** Instructors should use prompts that reflect natural behaviors. That is, prompts should resemble behaviors that are used naturally in environments.
- **Prompt only when the individual is attending.** Response prompts are designed to assist an individual in performing a specific target behavior, therefore it is important that the individual is attending to the task at hand. If the individual is not attending, then he or she will not learn the target behavior.
- **Provide prompts in a supportive, instructive manner.** The purpose of response prompting is not to punish or adversely affect individual behavior. Therefore, prompts should never be used in a corrective manner, rather, they should be used to facilitate learning of a target behavior.
- **Fade prompts as soon as possible.** In order for an individual to perform a target behavior independently, instructors must systematically fade the prompts.

System of Least Prompts

Before describing the system of least prompts, DSPs should understand two key concepts related to instruction and the use of prompts: *non-controlling* and *controlling prompts*.

Non-Controlling Prompt

Non-controlling prompts increase the likelihood of a current learner's response, but may not always elicit a correct response. For example, when teaching Eddy to brush his teeth, the DSP would use the least intrusive prompt first and allow Eddy the opportunity to respond. If he does not respond, then the DSP delivers the next level or prompt, up to the controlling prompt.



Controlling Prompt

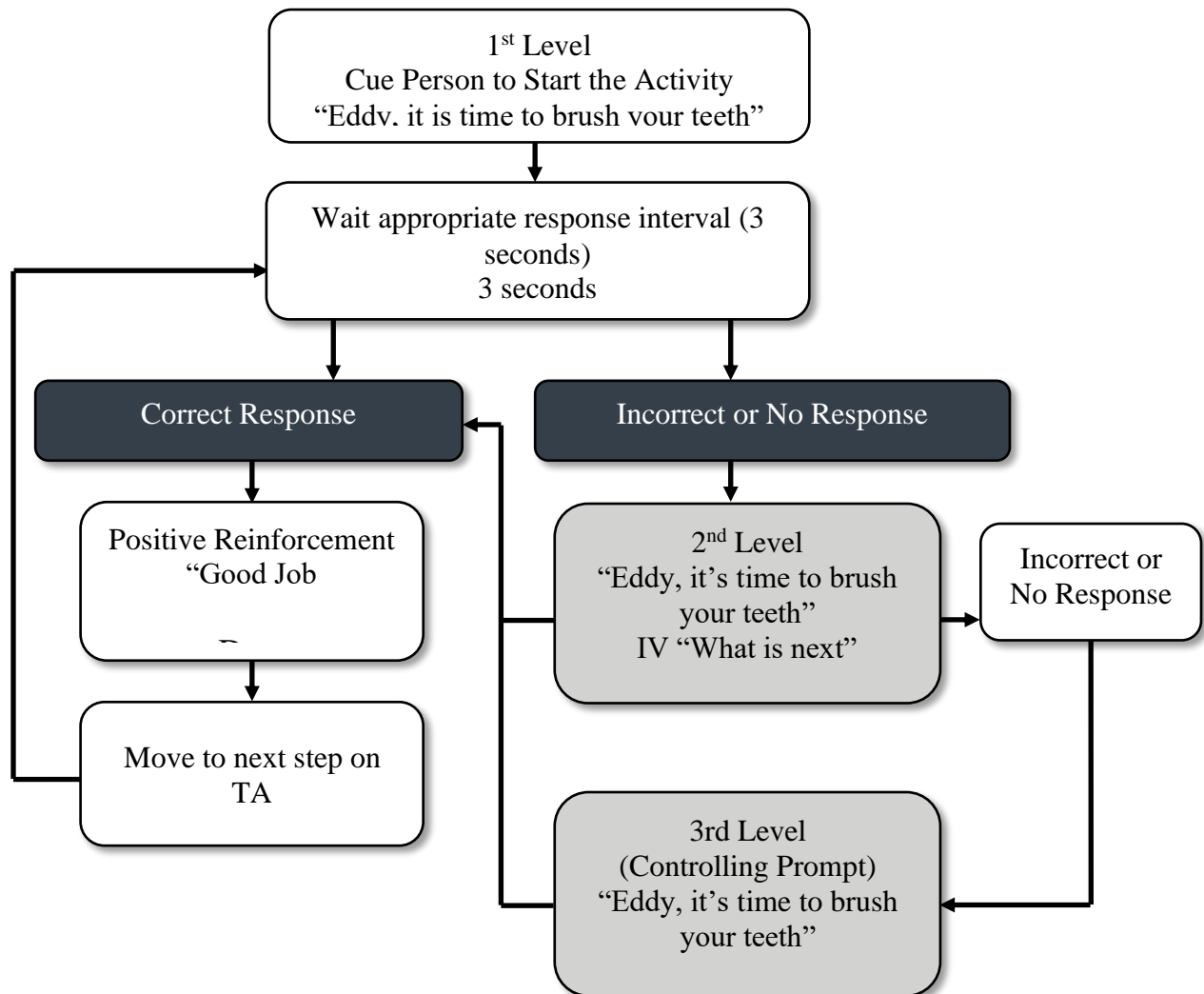
The controlling prompt is the prompt that reliably and consistently elicits a correct response from the learner. Consider Eddy who is learning to brush his teeth. The DSP determines that the controlling prompt is a verbal prompt – after the DSP delivers a verbal prompt, Eddy always performs the step correctly.

One of the most common strategies use to teach independent living skills is the system of least prompts. The systems of least prompts require the DSP to systematically use a hierarchy of prompts sequenced from the least to the most level of assistance. When implementing a system of least prompts, DSPs need to determine a minimum of three prompts in the hierarchy that will be used during instruction. The first level is the opportunity to respond without a prompt and the second and subsequent levels are prompts arranged from the least intrusive to the most intrusive concluding with the controlling prompt (the prompt that reliability elicits the correct response). DSPs also need to determine the length of the response interval (the time before a prompt is delivered). The DSP should determine the results to be used for each response and determine the appropriate feedback for correct and incorrect responses.

Consider the example of an individual who is learning to brush his teeth (figure 6.4). To begin instruction, the DSP would provide an instructional cue and allows the individual the opportunity to respond “Eddy, it is time to brush your teeth.” If Eddy does not respond within the appropriate response interval, the DSP systematically increases the amount assistance using the non-controlling prompts, “Eddy, what is next” and so on up to the controlling prompt “Eddy, I need you to pick-up the toothbrush.” During the initial phase of instruction, the DSP should verbally reinforce the individual after he completes each of the steps in task for brushing teeth. As the individual acquires the skill, the reinforcement should fade to natural levels.



Figure 6.4
Diagram of System



Data Collection

One way to ensure fidelity to instructional procedure is to develop an instructional script that outlines critical elements of instruction such as the measurable objective, setting and materials, teaching strategy, prompts, response interval, and error corrections. (Figure 6.5).



Figure 6.5

Example Instructional Script for Teeth Brushing

Instructional Script for Brushing Teeth	
Name: Eddy	Measurable Objective: Given a toothbrush and toothpaste, Eddy will independently brush teeth with 100% accuracy for 3 consecutive trials according to the steps outlined in the task analysis.
Setting: Bathroom	Materials: Toothbrush, tooth paste, sink, and running water
Teaching Strategy: System of Least Prompts	
Response Interval: 3 seconds	Controlling Prompt: Verbal (V) Non-Controlling prompts: Independent (I) Indirect Verbal (IV)
Error Correction	
Correct Response:	Provide verbal reinforcement “Great Job” for each prompted and unprompted correct response.
Incorrect Response:	Verbally identify the error “Eddy, you did not complete that step correctly” and provide a model. Ask Eddy to repeat the step.

The DSP should also collect data on individual performance in order to implement and adjust the program based on data patterns (Wolery, et al., 1992). Collecting meaningful instructional data can help DSPs determine how fast learner is acquiring and new task. A DSP, therefore, should develop easy to use data collection sheet that can be converted to display data graphically. Figure is an example of a least-to-most data collection sheet for brushing teeth.



Figure 6.6

Example Data Collection Sheet

Student: Eddy

Measurable Objective: Given a toothbrush and toothpaste, Jerry will independently brush teeth with 100% accuracy for 3 consecutive trials according to the steps outlined in the task analysis.

Setting: Bathroom

Materials: Toothbrush, toothpaste, sink, and running water

Steps	Session									
	Baseline			Instruction						
	1	2	3	4	5	6	7	8	9	10
Pick up the toothbrush	V	V	I V	I	I	I	I	I	I	I
Wet the brush	M	V	V	I V	V	V	I	I	I	I
Remove cap of toothpaste	M	IV	IV	I V	I	I	I V	I	I	I
Put paste on the brush	M	IV	I V	V	V	I V	I	I	I	I
Brush the bottom front teeth	M	V	V	V	I	I	I	I	I	I
Brush the bottom teeth on the left side	M	V	V	V	I V	I	I	I	I	I
Brush the bottom teeth on the right side	M	V	V	V	I V	I V	I	I	I	I
Brush the top front teeth	V	V	V	V	I V	I V	I V	I	I	I
Brush the top teeth on the left side	V	V	V	V	I V	I	I	I	I	I
Brush the top teeth on the right side	V	V	V	V	I	I	I	I	I	I
Brush tongue	V	V	V	V	V	V	I	I	I	I
Spit in sink	IV	IV	I V	I	I	I	I V	I	I	I
Rinse brush	V	V	I V	I	I	I	I	I	I	I
Put brush in holder	V	V	I V	I	I	I	I	I	I	I
Percent of unprompted Correct Responses	0	0	0	28	50	64	78	100	100	100

Summary Data									
%	%	%	%	%	%	%	%	%	%
100	100	10	100	100	100	100	100	100	100
90	90	90	90	90	90	90	90	90	90
80	80	80	80	80	80	80	80	80	80
70	70	70	70	70	70	70	70	70	70
60	60	60	60	60	60	60	60	60	60
50	50	50	50	50	50	50	50	50	50
40	40	40	40	40	40	40	40	40	40
30	30	30	30	30	30	30	30	30	30
20	20	20	20	20	20	20	20	20	20
10	10	10	10	10	10	10	10	10	10
0	0	0	0	0	0	0	0	0	0

As, you can see, data is collected for each step of the task analysis and the DSP collects both baseline and instructional data. Baseline data is used to provide a baseline for the individual's performance on the task and determine the controlling prompt. The DSP documents the type of prompt needed to elicit the correct response for both baseline and instructional data. Information on the data



sheet can be easily graphed to allow for a visual inspection of the data. This information allows the DSP to see if the employee is acquiring the new task. As you can see, this graph allows the DSP to determine if Eddy how quickly Eddy is learning how to brush his teeth. The graph indicates that after four instructional trials, Eddy could brush his teeth independently.

Compensatory and Other Support Strategies

There are other compensatory and support strategies that can be used to support an individual with independent and community-based skills.

- DSPs can create simple picture schedules to assist an individual with his or her daily schedule. Cell phones and iPads can be used to create video modeling programs to teach new skills.
- DSP can teach an individual to use memory/organizational notebooks to keep important information such as calendars, phone numbers, emails.
- Use alarms or timers to cue an individual when it is time to complete a task.
- Maintain predictable routines and structures.
- Minimize background distractions when the individual is trying to complete a difficult task.
- Use assistive technology such as a switch to turn on kitchen appliance; or Alexa technology to record grocery list.

Module Summary

This module provided information about how to identify training areas for independent skills. The module explored how to use ecological inventories to determine residential and community skills to teach individuals with disabilities. Specific teaching and data collection strategies were reviewed.

Key Takeaways

- Learning opportunities must be directly connected to the strengths and interests of an individual and be aligned with that person's direct needs.
- Skill should enhance a person with I/DD's quality of life in regard to physical well-being, material well-being, social well-being, productive well-being, emotional well-being, and civic well-being and be taught in



meaningful residential, community living, employment, and recreation environments.

- Use ecological inventories to analyze the demands of specific natural environments and to determine relevant skills needed to engage in these environments.
- DSPs should be familiar with an array of instructional strategies that can be used to teach the acquisition and maintenance of residential, community, and vocational tasks including response prompting and fading and compensatory strategies.

Reflection Questions

- How do you learn about what skills to teach a person with I/DD in residential and community settings?
- Have you used systematic instructional strategies in the past? What strategies did you use?
- What types of compensatory strategies have you used to support a person with I/DD to become more independent.



Module 7: Positive Behavioral Interventions and Supports





This module gives DSPs information about supporting individuals with challenging behaviors. The module will provide a review about how to understand behaviors from a different perspective (i.e. what are challenging behaviors, what influences behaviors, what behaviors are trying to communicate). The module will conclude with a discussion about how to support people using a positive behavior support framework.

At the conclusion of this module, you will be able to:

- Describe the function of challenging behaviors
- Describe what influences challenging behaviors
- Describe how to document and observe challenging behaviors using a functional behavioral assessment framework
- Describe how to develop positive behavior supports
- Describe the stages of behavior escalation and strategies to support and de-escalate.

The following table lists key terms you will need to know for Module 7.

Term	Definition
<i>Escape</i>	Behavior to leave a situation, activity, person, or area.
<i>Sensory/self-stimulation</i>	Behavior as a reaction to relieve sensory or self-stimulation needs such as having a headache or positive or negative reactions to sounds, smells, or touch.
<i>Access/tangible</i>	Behavior to get access to or have something such as food or an activity.
<i>Positive Reinforcement</i>	Strengthening the likelihood of a behavior happening again.
<i>Operationalized Description</i>	Description of the behavior including what happened before the behavior took place, the behavior itself, and what followed.
<i>Antecedent</i>	The situation, event, or condition that took place before a behavior occurred.
<i>Behavior</i>	An action or emotion exhibited by an individual.
<i>Consequence</i>	The situation and/or event that follows the behavior.
<i>ABC data sheet</i>	A data sheet that documents the antecedent, behavior, and consequence.
<i>Hypothesized function of the</i>	An educated guess as to why the behavior occurred.



<i>behavior</i>	
<i>Board-certified behavior specialist</i>	A specialist who has been educated and certified to analyze and treat unwanted behavior.
<i>Least restrictive alternatives</i>	Supporting an individual exhibiting unwanted behavior in the least-restrictive way. For example, removing the trigger of the behavior and providing reasonable choices and options.

Framework for Positive Supports

Challenging behavior can manifest in a variety of forms including, but not limited to, self-injury, aggression and destruction to property. Challenging behavior is often referenced as major contributor to more restrictive placements (Kennedy & Haring, 1992; Manete et al., 2010). Unfortunately, when a person with an intellectual disability exhibits challenging behavior, there is a potential that the overall quality of life for the person will diminish because of further segregation. The first step to support an individual who exhibits challenging behavior is to understand the function of a behavior.

The idea of thinking about the function of a behavior is important because it can help DSPs more fully understand the communicative intent behind the behavior. The DSP should analyze the function through the individual with a disabilities' perspective.

Function of Behavior

DSPs who have not had much exposure working with people with challenging behaviors may view behavior from a narrow framework and react or overact to behavior(s) when the behavior is:

- (a) harmful to the individual,
- (b) harmful to others, and
- (c) destructive.

It is important to recognize that the way a DSP responds to a specific behavior can impact how the individual with a disability will react in future situations.



A DSP should take steps to understand the function of the behavior and what outcome that behavior produces. When thinking about the function of behaviors, it is important to consider that most behaviors are learned and shaped by what happens before and after the behavior. Most behaviors serve one of several functions: *attention, escape, sensory/self-stimulation, access/tangible* (Alstot et al. 2015). The functions of behavior are outline in Table 7.1

Table 7.1
Function of Behavior

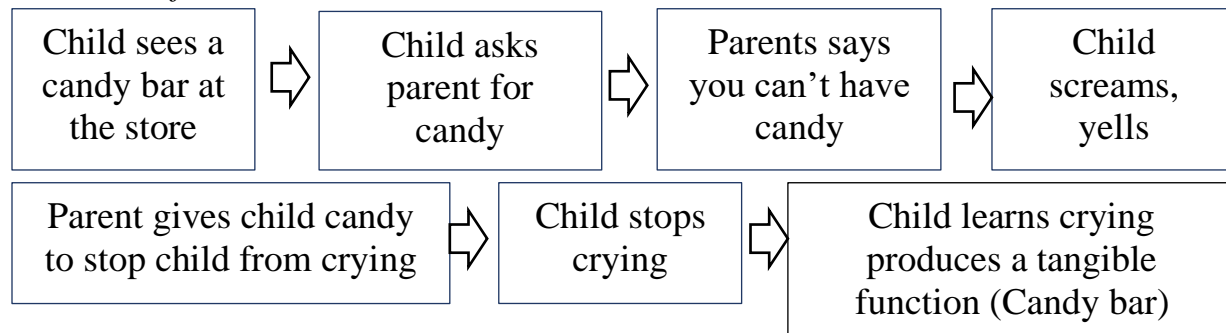
Functions of Behavior				
Attention <i>Behavior is a way to get attention</i>	Escape <i>Behavior is a way to escape an activity or situation</i>	Self-Stimulation <i>Behavior is for self-stimulation</i>	Sensory <i>Behavior is the reaction to sensory factors</i>	Tangible <i>Behavior is a way to get a tangible item</i>
<ul style="list-style-type: none"> • Attention from peers • Attention from DSPs • Attention from roommates • Attention from parents 	<ul style="list-style-type: none"> • Escape from difficult tasks • Escape from social situations • Escape from unknown tasks • Escape from a specific person 	<ul style="list-style-type: none"> • Sounds • Touch • Taste • Visual 	<ul style="list-style-type: none"> • Headache • Seizures • Smells • Sounds 	<ul style="list-style-type: none"> • Toys • Objects • Food • Activities

Consider the example of a child who is shopping at a grocery store and asks his parent for a candy bar (figure 7.2).



Figure 7.2

Function of Behavior



The parent tells the child that he can't have the candy because the child has not had lunch. The child begins to scream, yell, and flop on the ground. The parent needs to complete the shopping and tells the child that he can have the candy bar if he stops crying. The child's behavior was positively reinforced and the child learned that screaming, yelling, and flopping is the quickest way to get a tangible item.

Assessing the Function of a Behavior

When observing the function of a behavior, the DSP should document (a) the situations, events, and conditions that occurred prior to the behavior (antecedent), (b) an operationalized description of the behavior (behavior), and (c) the situations and events that follow the behavior (consequence). The three variables related behavior are documented: antecedent, behavior, consequence (Figure 7.3).

A DSP can use an ABC data sheet as a starting point for direct observation to document the function of a behavior. Consider the following example, a DSP is supporting Edward, a 16-year-old with intellectual disability who becomes upset, screams, and swears when asked to stop playing games on his Ipad. The DSPs uses an ABC data sheet to more formally learn about the function of the behavior (figure 7.4).



Figure 7.3

Description of the Antecedent, Behavior, and Consequence

Antecedent Situations, Events, Conditions prior to behavior	Behavior Clear description of the behavior	Consequence Situations and events that follow the behavior
Considerations <ul style="list-style-type: none">• Where does the behavior happen?• When does the behavior happen?• With whom does the behavior occur?• What is happening in the general environment (noise, light, smells)	Considerations <ul style="list-style-type: none">• Describe behaviors as clearly and concisely as possible.• Non example “Bill was aggressive today.”• Operational example, “Bill pinched the back of Janes hand”	Considerations <ul style="list-style-type: none">• Describe results as clearly and concisely as possible. There may be multiple results





Figure 7.4
Example ABC Sheet

Name: Edward				
Date/Time	Setting	Antecedent	Behavior	Consequence
3/27/21 6:45 am	In the bedroom/lying in bed	DSP entered room to tell Edward it was time to eat breakfast	Edward screamed “I don’t want to eat...I think you are stupid”. Yelled loudly.	Ignored language – prompted Edward that he needs to eat in 10 minutes
3/27/21 7:15 am	At the breakfast table	DSP told Edward he needs to stop playing games and get ready for school	Edward screamed “I want to finish my game.” He yelled loudly and threw his fork on the ground.	Ignored language and prompted Edward that he has ½ an hour to get ready for school
3/27/21 8:15 am	In the bedroom	DSP told Edward he needs to put down iPad and get ready for school. DSP physically removes iPad.	Edward screamed and threw socks at the DPS. He then laid on the floor and did not move.	DSP prompted Edward to get ready for school. Attempted to take iPad away. Screaming escalated. Edward missed the bus.

After the initial observation, the DPS should develop a hypothesized function of the behavior that is based on the ABC data collection (Figure 7.5). Based on the observation, the DSP hypothesized that Edward’s behavior was an escape behavior because he did not want to go to school.

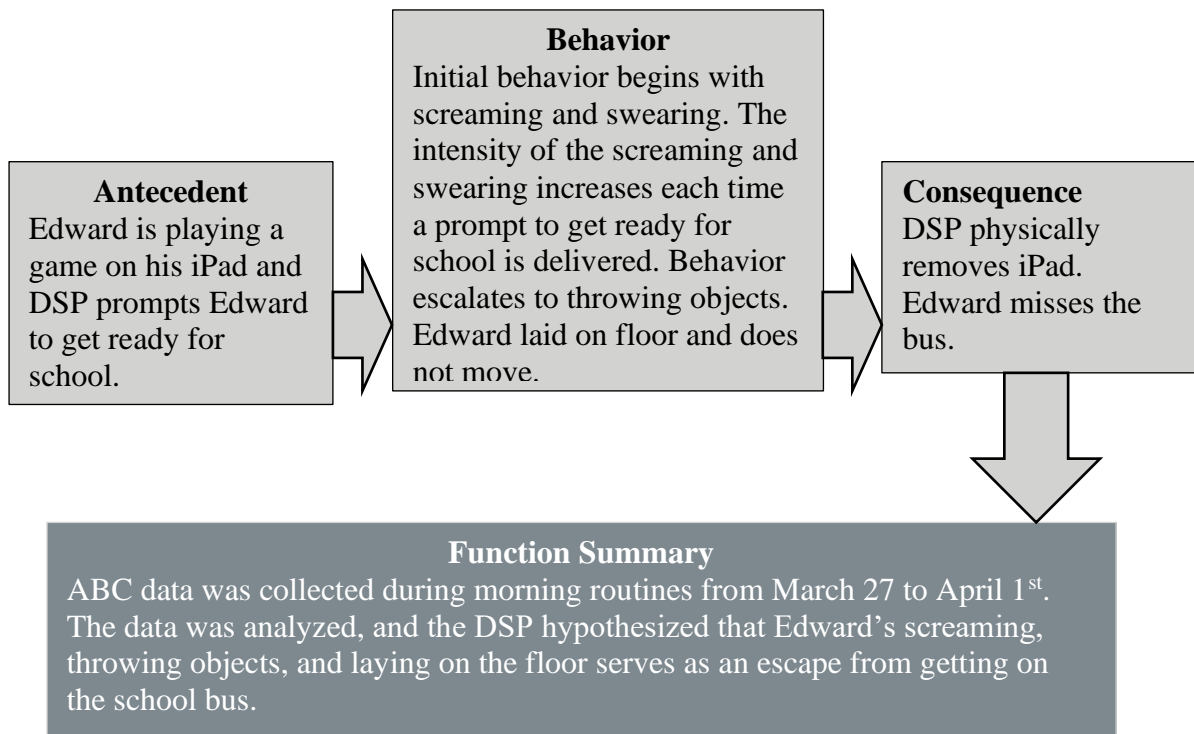


Figure 7.5.
Diagram of the Function of Behavior

It is important to note that DSPs should work with a professional trained in behavior assessments and interventions such a Board-Certified Behavior Analyst (BCBA, See <https://www.bacb.com/about-behavior-analysis/>).

Based on this information, the DSP should consider conducting further observations on the bus to determine if there are events that occur on the bus that Edward is trying to avoid. The DSP should develop strategies to teach more acceptable replacement behaviors and work with the school transportation to eliminate any behaviors on the bus that Edward is trying to avoid. In addition, the DSP should consider implementing other scheduling and routine adjustments to help Edward be more prepared to get on the bus.



Other Considerations When Determining the Function of a Behavior

DSPs should consider other factors that might be influencing or triggering a challenging behavior.

There may be underlying medical or physical concerns that may be the antecedent for a behavior. These include sleep issues, seizures, digestive issues, allergies, medications, headaches, hormonal changes, menstruation, sexual maturity, etc. There may also be underlying mental health concerns such as depression, anxiety, or obsession and compulsion.

A DSP should develop a monitoring system to determine if underlying medical or physical concerns. In the Figure 7.6 below, Edward was recently given a new medication to decrease episodes of self-injury. The DPS wanted to observe Edward to determine how the medication impacted Edwards's behaviors. As can be seen from the data collected, it appears the new medication is causing drowsiness and lethargy. The DPS may consult the medication side-effects pamphlet to determine if drowsiness is indeed a side effect and to determine how long these effects last. The DSP should develop supports for Edward during this timeframe to reduce the potential for challenging behaviors.

Another example, Ben a young transition-age youth with autism had the habit of constantly putting a hand in the back of his pants. Staff thought he was trying to get the negative attention of staff. However, when his mother took him to the doctor, he had a cyst on his tailbone that had to be surgically removed. This is an example that health concerns should always be elevated first when analyzing behavior.





Figure 7.6

Medication Monitoring Sheet

Name: Edward Medication Name: Risperidone Medication Dose: 1.5 mg daily/mornings			
Date and Time	Behavior		
	<i>Self-Injury, Hitting Side of Head</i>	<i>Tics</i>	<i>Drowsiness</i>
3/21/2021 8:00 am	None	None	Edward appeared to be drowsy with lethargy.
3/21/2021 1:00 pm	None	None	Edward appeared to be drowsy with lethargy.
3/21/2021 7:00 pm	Edward engaged in two episodes of mild SIB.	Minor Tics	Edward appeared to be drowsy with lethargy.
3/21/2021 8:00 am	None	None	Edward's seems drowsier today. He is having a time staying on task.
3/21/2021 1:00 pm	None	None	Edward appears to be very drowsy and nodding off to sleep
3/21/2021 7:00 pm	Edward engaged in One episodes of mild SIB.	None	Drowsiness seems to be tapering off

Stages of Behavior Escalation and Strategies to Support and De-Escalate

DSPs should be prepared to use the least restrictive alternatives to support an individual with I/DD who exhibits behaviors. To develop the least restrictive alternatives, the DSPs should understand the stages of behavior and ways to de-escalate. Figure 7.7 gives information about the stages of behavior and specific interventions you can use to de-escalate a behavior situation.



Figure 7.7
Stages of Behavior

Stages of Behavior and Intervention Ideas <i>Adapted from Colvin and Sugai, 1989</i>	
Behavior Stage	Intervention Ideas
Calm <ul style="list-style-type: none"> Individual is relatively calm and cooperative 	<ul style="list-style-type: none"> Maintain a clear and consistent environment Establish Behavioral Expectations Give positive feedback
Trigger <ul style="list-style-type: none"> Individual experiences conflict that causes the behavior to escalate Individual may displace anger on safe target (DSP, parent) 	<ul style="list-style-type: none"> Focus on prevention and redirecting behavior Remove/adjust the trigger (if appropriate) Use behavior momentum to shape behavior. Remind the individual to use replacement skills
Agitation <ul style="list-style-type: none"> Individual is unfocused and upset. Avoidance Challenging others 	<ul style="list-style-type: none"> Focus on reducing the individual's anxiety and increasing the predictability in the environment Use non-confrontational, nonverbal behavior Provide reasonable options/choices Set clear, reasonable, enforceable limits.
Acceleration <ul style="list-style-type: none"> Individual may become noncompliant Individual may loss rational thought Conflict becomes the sole focus 	<ul style="list-style-type: none"> Maintain a safe environment for the individual, yourself, and any observers. Use short phrases and allow for processing time Maintain calmness and detachment Use active listen Do not try to teach as this is not a teachable moment
Peak	<ul style="list-style-type: none"> Focus on crisis intervention procedures to maintain safety Remove non relevant observers



<ul style="list-style-type: none">• Individual lost control and may have temporarily lost the ability to think rationally.• Exhibits severe behavior (SIB, screaming, aggression to persons or objects)	<ul style="list-style-type: none">• Call for assistance if needed• Don't threaten consequences
De-Escalation <ul style="list-style-type: none">• Individual's behavior begins to subside• Drop in energy level	<ul style="list-style-type: none">• Focus on removing excess attention, help the individual regain composure with neutral requests• Allow cool-down time• Ensure the individual has regained control, look for signs (normal breathing, less tense appearance)
Recovery <ul style="list-style-type: none">• Individual's may feel shame, sorrow, fear, regret• May not be able to verbalize feelings	<ul style="list-style-type: none">• Focus on debriefing and transitioning back to routine• Problem solve and develop support plan• Document and determine antecedents and maintaining results

Final Considerations to Improve Quality of Life

When supporting people with I/DD who exhibit challenging behaviors, DSPs should value and practice positive behavior supports framework. A positive behavior supports framework requires DSPs to consider multiple component interventions that address a person's behavior and improve overall quality of life (Kincad et al., 2002). A positive behavior approach framework requires support staff change the way services and supports are delivered in order to reduce behaviors and enhance overall quality of life. These changes are reflected in nine common themes for positive supports outlined by Horner et al., (1990)

- **An emphasis on lifestyle changes.** Behavioral support should result in durable, generalized changes in the way an individual behaves, and these changes should affect the individual's access to community settings, to social contact, and to a greater array of preferred events.



- *Implications for DSPs:* DSPs should look for ways to expand access to integrated community settings. Supports should be tailored to the individual with a disability and information gathered from the PCP should be used to determine preferences.
- **Functional analysis.** Defining when challenging behaviors are likely to occur and what events are likely to be maintaining the behavior.
 - *Implications for DSPs:* DSPs should collect assessment data using the ABC format. If behaviors are complex, DSPs should work with a behavior specialist or BCBA who can conduct a functional behavior assessment.
- **Multicomponent interventions.** Single intervention to address a single challenging behavior is not sufficient. Intervention should instead manipulate many variables including movement of a person to less segregated settings, ignoring minor inappropriate behavior, choice making, instruction on new functional behaviors, increase access to preferred events, and staff training.
 - *Implications for DSPs:* DSP should implement interventions in applied community settings. Interventions should lead to increased access to inclusive education, employment, and recreation and leisure activities. DSPs should teach individuals to self-regulate. Self-regulation is a skill that people use to manage behaviors in certain situations. Self-regulation is a learned skill and the DSP should identify and teach individualized self-regulation skills.
- **Manipulation of ecological and setting events.** If broad behavior patterns are to be affected, a greater range of variables must be considered (not just manipulated the events that immediately precede and follow targeted behaviors). Staff should consider diet, living arrangement, noise level, sleeping patterns, and density of housing as contributing to the behavior.
 - *Implications for DSPs:* DSPs should monitor diet and access to healthy food choices. DSPs should ensure that living arrangements are appropriate such as living with preferred room/housemates and living with same-age peers. DSPs should ensure that individual with a



disability is engages in normal daily rhythms such as eating, sleeping, and exercising.

- **Emphasis on antecedent manipulations.** Modifying events in a setting so that the stimuli eliciting the undesirable behaviors are removed or reduced. Add activities that increase the likelihood of positive behaviors.
 - *Implications for DSPs:* DSPs should use information obtained from the PCP process to identify preferred activities and stimuli.
- **Teaching adaptive behavior.** Defining the function of a challenging behavior and teaching the individual acceptable ways of achieving that function (communication).
 - Implications for DSPs: DSPs should teach alternative methods to communicate wants and needs. DSPs should also respect the communicative intent of the individual. For example, if the individual uses an acceptable way to ask for a break while performing a difficult task, that request is respected.
- **Build environments with effective results.** Use differential reinforcement of alternative behavior (Alt R) and differential reinforcement of other behavior (DRO). Other strategies include identifying reinforcers that maintain a challenging behavior and deliver reinforcement at higher rate for desirable behavior.
 - *Implications for DSPs:* DSPs should use information from the PCP process to identify reinforcing activities. Preference assessments should also be used to identify highly reinforcing stimuli material.
- **Minimize the use of punishers.** The delivery of punishers for challenging behaviors is not desirable. DSPs should redirect to more appropriate behaviors and manipulate environment to reduce the undesired behavior.
 - *Implications for DSPs:* DSP should eliminate the use of punishers. DSPs should not withhold food or use food during this process.
- **Distinguish emergency procedures from proactive programming.** Distinguish between crisis interventions that are only used in emergency



situations and ongoing proactive strategies designed to produce substantive change.

- *Implications for DSPs:* DSPs should be trained to recognize that some behavior does not constitute a crisis. There are behaviors that can be extinguished.

Module Summary

This module was designed to provide DSPs information about supporting individuals with challenging behaviors. The module explored ways to examine the intent of a challenging behavior rather than simply acting to a behavior when it occurs. DSPs should examine a way to use a positive behavior support perspective to develop multiple interventions that reduce challenging behaviors and ultimately improve the quality of life of the individuals who are supported.

Key Take-Aways

- Challenging behavior often serves one of many functions including, attention, escape, self-stimulation, sensory, or tangible.
- DSPs should use the ABC's to determine the function of a behavior and develop plans based on this information.
- DSPs should examine other medical and physical factors that may influence a behavior.
- DSPs should value and practice positive behavior supports framework.



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