THE 411 ON DISABILITY DISCLOSURE:

A WORKBOOK FOR FAMILIES, EDUCATORS, YOUTH SERVICE PROFESSIONALS, AND ADULT ALLIES WHO CARE ABOUT YOUTH WITH DISABILITIES

Office of Disability Employment Policy

National Collaborative on Workforce and Disability NCWD For Youth

Navigating the Road to Work Making the Connection between Youth with Disabilities & Employment
The National Collaborative on Workforce and Disability for Youth (NCWD/Youth) is composed of partners with expertise in disability, education, employment, and workforce development issues. NCWD/Youth is housed at the Institute for Educational Leadership (IEL) in Washington, DC. NCWD/Youth is charged with assisting state and local workforce development systems to integrate youth with disabilities into their service strategies.

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Information is also available at http://www.disability.gov/, the comprehensive Federal website of disability-related government resources.

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This workbook provides the expertise about disclosing a disability, and YOU provide the support to a young person.
When you opened this workbook, you took an important step toward supporting a young person to determine whether he or she should disclose his or her disability. You made a decision to learn about disability disclosure and what it can mean for a young person with a disability in your life.

**Disclosure is a very personal decision, and takes thought and practice.**

Because disclosure is intentionally releasing personal and often highly sensitive information about oneself to others for a specific purpose, it is important for the individual to carefully consider what information he or she needs to share with whom and for what purposes. It is not essential that a person with a disability divulge all personal information about his or her disability. Some information is best kept private. Therefore, the individual needs to determine what information to share in order to best communicate how his or her disability affects his or her capacity in certain situations, and what he or she will need in order to access, participate in, and excel in the situation whether it be work, education, or community settings. The person with a disability must decide what and how much of sensitive information is necessary to reveal in order to obtain the needed accommodations.

Adults in the lives of young people with both visible disabilities and those with disabilities that are not apparent to others can benefit from using this workbook. This workbook helps you make informed decisions about teaching a young man or woman about his or her rights and responsibilities in disclosing his or her disability, a decision that will affect the young person’s educational, employment, and social life. This workbook will help you learn how to support a young person with a disability as he or she takes steps in becoming more independent and self-sufficient. In fact, making the personal decision to disclose a disability can make the young person more confident in himself or herself and the choices he or she makes.

This workbook is for you if:

- You want to understand the experiences of a young person with a disability;
- You want to understand how his or her disability influences the choices he or she makes;
- You want to help a young person explain his or her disability better to others;
- You are deciding how to advise a young person what and how to disclose; and
- You feel it would be beneficial for a young person to disclose his or her disability but feel unprepared or uncomfortable guiding him or her through this challenging process.

The ultimate goal of this workbook is to help you help the young man or woman in your life make an informed choice about disclosing his or her disability. Remember, this decision is the young person’s choice to make, and may vary based on the particular person, situation or setting, and need for accommodations. Trust the young person’s instincts and make sure he or she has what he or she needs to make an informed choice!
Introduction

This workbook is a companion publication to *The 411 on Disability Disclosure: A Workbook for Youth with Disabilities*. The workbook for youth is intended for young people to use on their own or with a group of peers. You may find it useful to complete this workbook at the same time that the young person you are supporting completes similar activities in the guide written for youth. The workbook for youth is available online at http://www.ncwd-youth.info/411-on-disability-disclosure.

Each unit contains a general statement of purpose, useful terminology, a discussion section, and activities to allow you to understand and practice the ideas presented throughout the unit. As you move through each unit, you will gain the information necessary to help the young person in your life make an informed decision about disclosure. We encourage you to complete the units in order, as the information in each unit is dependent on the information provided in previous units.

We also recommend you take your time completing each unit. There is a sizeable amount of information to process and it may take time to get through all of the units. It is important to become comfortable with the concepts, such as the models of disability, self-determination and informed choice, before moving on to other units concerning issues such as rights and responsibilities and accommodations.

While most of the activities can be completed individually, some of the activities require or suggest discussing particular issues and scenarios with the young person you are supporting to further your understanding of how best to help him or her.

A companion workbook, *The 411 on Disability Disclosure: A Workbook for Youth with Disabilities*, is available for young people to use on their own or with a group of peers. You may find it useful to complete this workbook for adults at the same time that the young person you are supporting completes similar activities in the guide written for youth. The workbook for youth is available online at http://www.ncwd-youth.info/411-on-disability-disclosure.
Before we get into the nitty gritty of disclosure, the authors of this document wanted to take a moment or two for you to have an opportunity to think about the term “disability”, and how you react not only to the word, but to the concept. A lot of times our perception and reaction to certain terms is a result of societal pressures, preconceived notions, and expectations. A key purpose of this document is to address the stigma surrounding the term “disability” with families, educators, youth service professionals, and other adult allies. Adults supporting youth with disabilities may be having a hard time grappling with this issue, and in some cases, they may not even know it. Take a moment to write out what you think disability is and what your perceptions of it are before we move ahead.

Disability is: __________________________________________________________

_____________________________________________________________________

_____________________________________________________________________

Hearing the word “disability” makes me feel: ________________________________

_____________________________________________________________________

_____________________________________________________________________

My expectations of people with disabilities in school settings are: ______________

_____________________________________________________________________

_____________________________________________________________________
My expectations of people with disabilities in work settings are: ______________________________
____________________________________________________________________________________
____________________________________________________________________________________

My expectations of people with disabilities in social settings are: ______________________________
____________________________________________________________________________________
____________________________________________________________________________________

Disability culture is: ___________________________________________________________________
____________________________________________________________________________________

Definitions for the various terms discussed in Unit 1 are provided in the Glossary located in the back of this workbook.

We understand that the “D” word makes a lot of people uncomfortable. Some people would rather use terms like “special needs,” “differently-abled,” or even “handicapable.” Some people believe purposely lessening the effect of a person’s disability does him or her a service. In reality, it disenfranchises people with disabilities from accessing the civil rights protections afforded to them by statutes like the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act, the Individuals with Disabilities Education Act (IDEA), and many more.

What is disability?
Disability is not a bad word. It is not a negative word. It is not a dirty word. By using the term disability, you are making an important connection to a diverse group of people who have struggled throughout history to be treated first and foremost as people; you are making a connection to a civil rights struggle that is over 200 years old in the United States, and much older than that when looked at internationally. Disability has a long history in this country; it dates back to the signing of the U.S. Constitution, the Civil War, and even farther.
The Americans with Disabilities Act (ADA) defines disability as:

1. A physical or mental impairment that substantially limits one or more major life activities;
2. A record of such an impairment; or
3. Being regarded as having such an impairment.

The ADA also articulates a new framework of national disability public policy. This framework incorporates the goals of assuring equality of opportunity, full participation in all aspects of society, independent living, and economic self-sufficiency. Underlying policy assumptions and objectives drive each of these major themes. For example:

- **Disability** is viewed as a natural part of the human experience; it is not something to be ashamed of or feared. People with disabilities are not broken or damaged goods in need of being fixed.

- **Individualization** is a major underpinning of disability public policy. Decisions about someone with a disability are to be based on the individual’s strengths, resources, priorities, concerns, abilities, and capabilities, rather than on stereotypes, assumptions, and misperceptions.

- **Equal opportunity** in the disability context means that programs and services must be accessible to, and usable by people with disabilities in the most integrated setting possible, considering the person’s unique needs and circumstances.

- **The full participation** tenet incorporates individual and family empowerment, self-determination, self-advocacy, informed choice, and active participation of a person with a disability, and often his or her family, in the decision-making process.

As a consequence of the ADA and the IDEA, more and more students with disabilities are being enrolled in general education classes ("mainstreamed") and speak with, work with, and interact with their peers with and without disabilities on a regular basis. While this is a great step in the direction of creating a fully inclusive society in the process, students with disabilities may lose a connection to the disability community and all that it could bring to empower their lives. Inclusion doesn’t lessen or wipe away a student’s disability, and in fact, it makes the case for giving youth with disabilities connections to the disability community that are much more important. In addition to inclusion, students with disabilities need to have opportunities:

- To be mentored by professional adults with disabilities, and encounter a variety of role models, mentors, and peers with disabilities;
- To get involved in disability leadership organizations like the National Youth Leadership Network or State level Youth Leadership Forums (Resources for these and other organizations are in Appendix A found at the end of Unit 1 on page 16);
- To learn about the history of people with disabilities and their achievements of people with disabilities; and
To gain an understanding of their rights and responsibilities under different pieces of disability public policy (This topic is addressed in Unit 5).

The opportunity to participate in programs with other youth with disabilities contributes to their overall development and well-being by providing them with a sense of connectedness and a venue for sharing common experiences. This does not mean, however, that these should be the only opportunities that youth with disabilities have; they should also be supported and encouraged to fully participate in programs and activities with youth who do not have disabilities. Doing so will allow them to develop the resiliency skills that all youth need especially youth with disabilities.

Throughout history, different models of disability have been used to explain and sometimes justify the treatment (or mistreatment) of people with disabilities. These models were and are frameworks or lenses for how society views and treats people with disabilities. People with disabilities have been viewed as deserving of pity, helpless, and in need of care. Sometimes they are seen as “supercrips” — people who are inspirational and super human, achieving the incredible in spite of their disability. These portrayals are perpetuated in the media and pop culture of the time.

As times and attitudes have changed, so has the model of disability depicted in the media and accepted in society. With the rise of the disability rights movement and the passage of the ADA, the perception of disability shifted from one in which a disability was equated with “sinfulness”, or a need to be “fixed,” to one that includes disability as a part of diversity. As a result, there has been an additional push for society, mainstream culture, and government to ensure the full participation of people with disabilities in everyday life.

As young people with disabilities are developing and struggling with issues of self-esteem, disability disclosure, body image, and other personal issues, it is important for them to understand the perceptions society may have of them. Table 1 defines and illustrates the various models of disability, and gives examples cited from the media, society, and pop culture. Be aware that although society is moving toward an inclusive view of disability, old views are slow to disappear. On any given day, a youth with a disability may encounter people who perceive him or her through any of the various models below.

For additional information on the shift in disability policy, please refer to Emerging Disability Policy Framework: A Guidepost For Analyzing Public Policy (Silverstein, 2000). For a more in-depth history of the Disability Rights Movement and Disability Culture, mentors may want to read No Pity: People with Disabilities Forging a New Civil Rights Movement (Shapiro, 1994).

Disability Culture and Pride

From the outside it might seem that because disability can be so many things, differing in severity and in how it is demonstrated or
### Table 1: Models of Disability*

<table>
<thead>
<tr>
<th>MODEL</th>
<th>DEFINITION</th>
<th>EXAMPLE(S)</th>
</tr>
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</table>
| Moral Model                  | People with disabilities are afflicted by the devil, or their disability is the result of a sin or punishment for wrongdoing by them or their family. In other words, the “external” disability represents a spiritual or internal “defect.”                                                                 | • Captain Hook (PETER PAN)  
• Quasimodo (THE HUNCHBACK OF NOTRE DAME)  
• Dr. Claw (INSPECTOR GADGET)  
• King Richard III (SHAKESPEARE’S RICHARD III) |
| Medical Model                | People with disabilities are broken and need to be fixed. For example, people who were unable to walk were often forced to wear heavy braces or undergo experiments and radical treatments to make them “whole” or “normal” again.                                                     | • ONE FLEW OVER THE CUCKOO’S NEST                                                            |
| Charity Model                | People with disabilities are tragic and deserve pity and protection from the demands of society. The term “handicap” came from the image of a person with a disability during the Industrial Revolution, who had a “cap in hand” to beg in the streets. | • Laura in THE GLASS MENAGERIE  
• POLLYANNA  
• Tiny Tim from A CHRISTMAS CAROL  
• Oompa Loompas from CHARLIE AND THE CHOCOLATE FACTORY |
| Social/Civil Rights Model    | Under this model, systems, laws, policies, environments, and relationships that continue to keep people with disabilities isolated from society all need to change. This model promotes “inclusion,” “full participation,” “self-sufficiency,” and “independent living.”                                                                 | • David Rappaport in THE WIZARD (1980s television show)  
• Daniel Day Lewis in MY LEFT FOOT  
• Paul Wellstone  
• Ed Roberts                                                                 |
| (1980-1990s)                 |                                                                                                                                                                                                          |                                                                                                 |
| Cultural Minority Model      | People with disabilities join together and form a separate cultural group similar to those that arise from ethnicity, race, or religion. The cultural minority model emphasizes the need to appreciate the differences that come out of being a person with a disability, as one would appreciate differences in ethnicity, race, or religion. Out of this model came the assertion that people should embrace the idea of a “disability culture” and be “Disabled and Proud!” | • Linda from SESAME STREET  
• Actor Mitch Longley from LAS VEGAS  
• Actor Robert David Hall from CSI  
• Christopher Snow, a character in Dean Koontz’s novels  
• Lincoln Rhyme, a character in Jeffrey Deaver’s novels                                                                 |
| (1990s-present)             |                                                                                                                                                                                                          |                                                                                                 |

*Adapted from NCWD/Youth’s “Paving the Way to Work: A Guide to Career–Focused mentoring” (2006)
perceived, that there isn’t much that let’s say a person with a learning disability shares with an individual who uses a wheelchair. However, both of these individuals have to accommodate their disabilities to integrate into society while still dealing with other people’s low expectations. Just as a person with a speech impediment may fear public speaking, a person who uses a wheelchair may fear that people will focus more on the wheelchair than on what he or she is trying to say. The shared fear — the common experience of having been subjected to oppression and low expectations — and how the individual with a disability reacts to it all ties people with disabilities together in what is starting to be called a disability culture.

Out of a common sense of community and history, this culture began to develop among people with disabilities. The feeling of sharing a common experience is the initial sign of something more than just coincidences and experiences, but a deeper level of kinship. People with disabilities have a history of being grouped together. Whether in the past in hospitals and institutions, segregated schools, and concentration camps, or today at protests, conferences, and organizations, this group identity continues to grow and evolve.

“People with disabilities have forged a group identity. We share a common history of oppression and a common bond of resilience. We generate art, music, literature, and other expressions of our lives and our culture, infused from our experience of disability. Most importantly, we are proud of ourselves as people with disabilities. We claim our disabilities with pride as part of our identity. We are who we are: we are people with disabilities” (Brown, 1996).

Disability culture emerged as a result of the oppression that people with disabilities face on political, social, economic, and cultural levels. Part of it is a direct result of feeling as though they cannot fit in the mainstream non-disabled culture, yet they still want the basic tenets of culture (e.g., knowledge, art, history, morals, laws, and customs). It’s not having to conform for others, and not having to explain why they should not have to. It’s being able to relate to people across disability types because although their needs and experiences may differ, they all face day to day life in a society that was not built around their different abilities and they continually have to prove themselves to people who have no clue what it’s like to be a person with a disability.

According to Gill (1995), the functions of a disability culture include:

1) **Fortification:** definition and expression of the group of individuals’ value as a community that gives its members energy and endurance against oppression.

2) **Unification:** The expression of the group’s beliefs and heritage in cultural activities which brings its members together, promotes mutual support, and reinforces their shared values.

3) **Communication:** Expressions of art, language, symbols, and rituals the group’s members use to describe to the world and to each other who they are and what makes them distinct as a community of people.

4) **Recruitment:** Expressing the group’s culture counters the historical social marginalization of its members through a positive and defiant celebration of their distinctness as a group. It encourages people with disabilities to “come out” and
join the community, integrating their disabilities into their own identities, and making them feel like they belong.

Oftentimes, when a young person with a disability wants to embrace his or her connection to the disability culture, people without disabilities react with skepticism. Families may perceive this as a rejection of the morals, values, and culture that they raised their child with. In fact, this is not a rejection of how one was raised, but instead an acceptance that the makeup of a single individual is derived from multiple sources. It doesn’t lessen one’s ties to a particular racial, ethnic, religious, or sexuality group. Cultural identity is not an “one or the other” type of choice. Instead, when a person with a disability chooses to be part of the disability community and to feel part of the larger culture, it enables him or her to feel a sense of belonging to something bigger than himself or herself that can provide a different type of support than he or she may be receiving in other areas of his or her life.

Embracing disability culture may not be for everyone with a disability. For those that wish to do so, however, feeling a sense of pride in being a person with a disability and a member of the disability community is a positive thing. A student with dyslexia who is being teased for being “dumb” encounters similar challenges of exclusion as those encountered by a student who uses a wheelchair and is left out of a physical education activity that takes place on a grassy field. The specific type of oppression may be different or may vary in subtlety, but both experiences generate feelings of isolation and decreased self-worth.

The concept of disability pride is an emerging one that has spun off of the argument that people with disabilities have a common culture. Anytime people with disabilities come together, whether in hospitals, schools, camps, protests, workshops, or at conferences, a stronger sense of community and belonging is felt.

Sarah Triano, a leader in the disability community, defines disability pride as follows:

“Disability Pride represents a rejection of the notion that our physical, sensory, mental, and cognitive differences from the non-disabled standard are wrong or bad in any way, and is a statement of our self-acceptance, dignity and pride. It is a public expression of our belief that our disabilities are a natural part of human diversity, a celebration of our heritage and culture, and a validation of our experience. Disability Pride is an integral part of movement building, and a direct challenge to systemic ableism and stigmatizing definitions of disability. It is a militant act of self-definition, a purposive valuing of that which is socially devalued, and an attempt to untangle ourselves from the complex matrix of negative beliefs, attitudes, and feelings that grow from the dominant group’s assumption that there is something inherently wrong with our disabilities and identity” (Triano, 2006).
Appendix A: Disability Leadership Organizations for Youth

One way to help youth with disabilities develop leadership skills is to encourage them to get involved in leadership organizations of all types such as school and community service clubs and student chapters of professional and civic organizations. Youth with disabilities may find it especially fulfilling to get engaged in disability interest and advocacy groups. The following youth leadership organizations seek to engage youth with disabilities in national, state, and local advocacy and leadership development opportunities.

The **Youth Leadership Forum (YLF)** assists states in providing youth leadership training for high school juniors and seniors with disabilities. Students selected as delegates attend a four-day event in their state capitals to develop leadership, citizenship, and social skills. By providing a framework of history and an atmosphere of encouragement, the forums offer peers opportunities to learn from one another as they explore common challenges and experiences. For more information, visit the website for the Association of Youth Leadership Forums at http://www.montanaylf.org.

The **National Youth Leadership Network (NYLN)** is dedicated to advancing the next generation of disability leaders. NYLN provides a national voice for young leaders with disabilities. Originally sponsored by several federal agencies and led by the U.S. Department of Education, NYLN promotes leadership development, education, employment, independent living, and health and wellness among young leaders. Now a non-profit organization, the Network’s activities include quarterly newsletters, educational teleconferences, mentoring opportunities, and more. For more information, visit http://nyln.org.

**Youth Information, Training, and Resource Centers (YITRCs)** are 21 organizations funded by the U.S. Department of Health and Human Services’ (DHHS) Administration for Children and Families (ACF) and Administration on Developmental Disabilities (ADD). These youth-led organizations received grants to develop information, resource, and training centers for youth (ages 13-17) and emerging leaders (ages 18-30) with developmental disabilities. For more information, visit http://www.addyic.org.
Unit 2: Introduction to the 5 Self’s and Goal-Setting

PURPOSE

The purpose of Unit 2 is to introduce you to the process and values that we like to call the 5 Self’s (i.e., Self-Advocacy, Self-Determination, Self-Esteem, Self-Efficacy, Self-Sufficiency), and help you better understand if the value of each of these and the role they can play in helping you support youth with disabilities. A questionnaire will then help you examine your perceptions about the young man or young woman in your life’s strengths and consider what areas you would like to help them develop. We strongly suggest that you read the discussion section on page 2-3.

YOUR ROLE

As the young person begins developing and utilizing each of the 5 Self’s and sets some goals for him or herself, your role is to empower, not enable him or her. A person cannot achieve self-determination, self-advocacy, self-esteem, self-sufficiency, and self-efficacy in a culture of low expectations. Remember, once he or she leaves high school, the choice to disclose is his or hers. Your job is to be as supportive as possible and to provide him or her with tips, tools, and information so that they can make the most informed decision possible. This is not to say that everything will be perfect, that the young person will always have his or her needs met to the utmost satisfaction or that she or he will never have a negative experience disclosing his or her disability. Nonetheless it is your job to help prepare him or her to exercise the 5 Self’s effectively.
You may know some of these words already, or you may have just heard them in passing. First, define the words as you understand them. Then, check your definitions against the glossary located in the back of this workbook. Here are the terms used in Unit 2:

<table>
<thead>
<tr>
<th>Accommodation</th>
<th>Self-advocacy</th>
<th>Self-esteem</th>
</tr>
</thead>
<tbody>
<tr>
<td>Empower</td>
<td>Self-determination</td>
<td>Self-sufficiency</td>
</tr>
<tr>
<td>Informed choice</td>
<td>Self-efficacy</td>
<td></td>
</tr>
</tbody>
</table>

Accommodation: ________________________________________________________________

Empower: _________________________________________________________________

Informed choice: ___________________________________________________________

Self-advocacy: _____________________________________________________________

Self-determination: _______________________________________________________

Self-efficacy: _____________________________________________________________

Self-esteem: ______________________________________________________________

Self-sufficiency: _________________________________________________________
One of the key ways that adults define themselves and develop a sense of identity is through the many choices they have made throughout their lives. Young people as well as adults often struggle with making good informed decisions.

The largest influence in the lives of all youth is their families. Parents, guardians, siblings, and extended relatives all have an impact on how individuals not only perceive themselves, but also on how they perceive the outside world. One of the biggest challenges faced by all people with disabilities is low expectations. It can be as subtle as a child with a disability having no chores in a multi-child household, or as obvious as telling a person with a disability that they can’t go to college because people like them don’t go there. As young people grow, learn, and begin forming their beliefs and values, the first place they look is to their family. If a young person sees that his or her family behaves in a way that makes him or her feel ashamed or invisible, he or she will assimilate this into his or her own feelings of self-worth.

Out in the real world, teenagers make important choices such as choosing a part-time job, deciding which classes to take, selecting someone to date, and deciding what to do in their free time. These decisions aren’t always easy. Some young people can use help in making these decisions, while others may decide to make them on their own. Remember that some decisions must be made without having all of the necessary information available. Not all decisions can be well supported, but it’s important that decisions be based on the information that is available and for the young person to understand the decision-making process.

Youth are rarely taught about informed choice while in high school. **Informed choice** is the process of making a decision after considering relevant facts and weighing the pros and cons of the decision. Making informed choices is a skill that must be practiced, encouraged, reflected upon, and then practiced some more in order to be acquired. This process requires a person to collect information before making a decision. A young person may be given information or he or she may need to do some research on his or her own perhaps by going online or talking to people. Informed decision-making is a skill that a young person will benefit from many times in his or her life when he or she has to make crucial decisions. Furthermore, it enriches an individual’s ability to achieve each of the 5 Self’s, as described below.

**Introduction to the 5 Self’s**

The major goals of the ADA are full participation, equality of opportunity, independent living, and economic self-sufficiency. Regardless of disability, these are things that everyone wants. Nevertheless society’s perceptions of disability and of what people with disabilities can achieve can make these goals difficult to achieve. Research has, for a long time, emphasized the role that self-advocacy and self-determination play in helping youth with disabilities successfully transition to adulthood. For most people not actively engaged in the disability community, however, these may be unfamiliar terms.
### Table 2: The 5 Self’s

<table>
<thead>
<tr>
<th>TERM</th>
<th>DEFINITION</th>
<th>APPLICATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-Determination</td>
<td>Self-determination is “the attitudes and abilities required to act as the primary causal agent in one's life” (Wehmeyer, 1992, p. 305). A self-determined person makes use of knowledge about his or her own strengths, limitations, and characteristics in order to act in a manner which is self-realizing (Wehmeyer, Kelchner, &amp; Richards, 1996).</td>
<td>A student makes a choice to attend a college that has the major and extra curricular activities he or she is interested in, and in a place he or she would like to live.</td>
</tr>
<tr>
<td>Self-Advocacy</td>
<td>Self-advocacy is the act of advocating for oneself and speaking out for what one believes in. Teaching self-advocacy involves teaching someone how to make decisions and choices that affect his or her life so he or she can become more independent. It also involves teaching someone about his or her rights, as well as responsibilities. (Hayden &amp; Shoultz, 1991).</td>
<td>A student takes an active role in his/her IEP meeting and determining what accommodations he or she needs to do his or her best.</td>
</tr>
<tr>
<td>Self-Esteem</td>
<td>Self-esteem is “the collection of beliefs or feelings that we have about ourselves, or our ‘self-perceptions.’ How we define ourselves influences our motivations, attitudes, and behaviors and affects our emotional adjustment” (Nemours Foundation, 2008). Instead of responding to a bad test score as “I’m an idiot,” a person with high self-esteem will be more likely to respond optimistically with a desire to work to find the solutions to do better next time.</td>
<td></td>
</tr>
<tr>
<td>Self-Efficacy</td>
<td>Self-efficacy is a belief in one’s ability to obtain a goal (Martin &amp; Marshall, 1995). “Self-efficacy beliefs provide the foundation for human motivation, well-being, and personal accomplishment” (Pajares, 2002). An example of self-efficacy is someone knowing that he or she wants to be a teacher in the future and believing in him or herself while going to school, taking tests, and learning the skills needed to achieve this goal.</td>
<td></td>
</tr>
<tr>
<td>Self-Sufficiency</td>
<td>In the most extreme case, a self-sufficient person would be able to supply all of his or her own basic needs without the intervention of anyone else - from physical needs such as food and shelter to intangible needs such as happiness (Richards, 2003). An example of self-sufficiency is someone graduating from college, deciding to live on his or her own in the community, and figuring out how to pay bills, budget, and to get the services he or she need to do so successfully.</td>
<td></td>
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</tbody>
</table>
Self-determination is the desire, ability, and practice of directing one’s own life. You can think of it as an umbrella that covers the very important and personal matters that make up the individual. In a lot of ways, mastery of self-determination skills empowers youth to achieve all the other Self’s.

A self-determined person can:

- Set goals;
- Make decisions;
- Identify and evaluate options;
- Solve problems;
- Speak for him or herself;
- Understand required supports; and

Practicing skills in support of the 5 Self’s helps a young person to make important choices and informed decisions in his or her life based on what he or she can do, what he or she is interested in, and what he or she feels most passionate about. People who have these skills accept themselves, respect themselves, and value themselves for who they are and what they have to offer to others.

When people are self-determined, they can more easily identify their short-term and long-term personal goals. Short-term goals are steps you take to get to your long-term goal. In addition, self-determined individuals understand that some personal goals (whether short-term or long-term) can be reached independently, while also recognizing that all people seek out others to help them achieve all their goals. Self-determination empowers people to seek assistance when needed.

One important decision that many young people face is whether or not to disclose their disability. The decision to disclose a disability belongs solely to the person with the disability, not to the family of the person, not to his or her educator, not to a service provider, and not even to a mentor. Your role in supporting a young man or woman with a disability is to empower or support and promote him or her in incorporating the 5 Self’s into his or her behavior. Some ways that you can do this include:

- Encouraging him or her throughout the decision-making process;
- Providing a “safe place” to practice disclosure conversations and role play possible scenarios; and
- Providing information about his or her rights and responsibilities related to disclosure.

While there are no requirements that a person with disability disclose his or her disability to anyone, disclosure is necessary if the person wishes to receive accommodations at work or in postsecondary school. Strengthening skills in each of the 5 Self’s enables youth with disabilities to disclose more successfully by confidently articulating their disability-related needs in different settings.

A self-determined person with decision-making skills will be better equipped to weigh the pros and cons and consider all potential outcomes of disclosure. If a young
person decides to disclose his or her disability after thoughtful reflection on the subject, it is important that he or she practice doing so with someone. It is important that the young person receives supportive and gracious space and that he or she feels comfortable making mistakes while practicing disclosure conversations.

This workbook was created to help guide you in supporting a young person with a disability as he or she makes an informed decision about disclosure. It is also intended to help you prepare him or her to disclose information in a confident and effective manner if necessary.

Complete the following questionnaire to determine to what extent the young person is already exhibiting behaviors consistent with the 5 Self’s and to assess his or her ability to disclose. Review your answers with the young person and discuss his or her strengths, limitations, and your own pre-conceived notions. Use the discussion as an opportunity to provide useful information that will empower him or her to highlight personal strengths and to build his or her capacity in areas of limitation.

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### Assessing the Young Person on the 5 Self’s

In your opinion, how much does the young person with a disability know about himself or herself and his or her disability? Is he or she exhibiting the 5 Self’s? Complete the questionnaire below. For each question, select the one response — Yes, Sometimes, or No — that best describes your perception of the young man or woman with a disability.

<table>
<thead>
<tr>
<th>QUESTIONS</th>
<th>YES</th>
<th>SOMETIMES</th>
<th>NO</th>
<th>Goal Setting</th>
<th>Priority for</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Does the young person know his or her strengths in school?</td>
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<td>2. Does the young person know what he or she does well outside of school?</td>
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<td>3. Can the young person easily explain his or her skills and strengths to other people?</td>
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<td>4. Does the young person know how he or she learns best?</td>
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<td>5. Does the young person inform teachers how he or she learns best?</td>
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<td>6. Does the young person inform employers how he or she learns best?</td>
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<td>7. Does the young person ask for help when he or she needs it?</td>
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<td>8. Does the young person take responsibility for his or her own behavior?</td>
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<td>9. Does the young person feel proud of him or herself?</td>
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<td>10. Does the young person set short-term and long-term goals for him or herself?</td>
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<td>11. Does the young person create lists to help achieve his or her goals?</td>
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<tr>
<td>QUESTIONS</td>
<td>YES Setting</td>
<td>SOMETIMES</td>
<td>NO</td>
<td>Priority for Goal Setting</td>
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<td>12. Does the young person attend his or her own IEP or 504 meetings¹?</td>
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<td>13. Does the young person disclose his or her disability to others?</td>
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<td>14. Does the young person feel comfortable about the reaction received after he or she informs someone about his or her disability?</td>
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<tr>
<td>15. Does the young person practice disclosing his or her disability to others?</td>
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<td>16. Does the young person describe his or her disability differently depending on whom he or she is disclosing to or the setting?</td>
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<td>17. Are there times or situations when he or she choose not to disclose?</td>
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<td>18. Does the young person know what “reasonable accommodation” means?</td>
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<td>19. Does the young person know what accommodations he or she needs in school in order to be successful?</td>
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<td>20. Does the young person know what accommodations he or she needs on the job in order to be successful?</td>
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<tr>
<td>21. Does the young person know what accommodations he or she needs socially in order to be successful?</td>
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<td>22. Does the young person practice asking for the accommodations he or she needs in school?</td>
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<tr>
<td>23. Does the young person practice asking for the accommodations he or she needs in work?</td>
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<tr>
<td>24. Does the young person practice asking for the accommodations he or she needs in social settings?</td>
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¹ See the glossary for definitions of IEP and 504 meetings.
Once you have completed the questionnaire, review your answers with the young person and ask if he or she agrees with your perceptions of his or her current behaviors, strengths, and limitations. If the young person disagrees with your answer for any question, discuss your areas of disagreement to help you get a better picture of the young person’s actions, self-knowledge, and feelings. After some discussion, adjust your answers where needed based on your new understanding of the young person.

If you answered “Yes” to many of the questions, you and the young person you are working with should be very proud. The young person you are working with definitely has a good sense of himself or herself and is taking responsibility for his or her own life and needs. This means he or she is well on the way to being a very self-determined individual! Of course, there is always room for improvement.

If you answered “Sometimes” to many of the questions, the young person likely possesses some very good skills in understanding him or herself and his or her disability. Yet there are still some specific areas that need to be developed.

If you answered “No” to many of the questions, the young person is likely just beginning to understand him or herself and his or her disability. You can support the young person in identifying opportunities to build his or her strengths in these areas.

Whether the young person is already very self-determined or is just beginning the journey to self-determination, spend some time talking about his or her strengths as well as the things he or she needs to improve upon.

Find out which areas he or she finds most challenging and which he or she would like to grow in. Encourage him or her to seek support from other caring individuals including family members and peers and to ask for assistance in developing some short-term goals.

To prepare for the next activity on setting short-term goals, discuss with the young person what priority to give to each area he or she needs to improve. Use the last column of the questionnaire to record how you and the young person have agreed to prioritize the areas — place a “1” in the column for the area you agree is first priority, a “2” next to the area that is second priority, and so on.

Now that you have some sense of the 5 Self’s and where the young person stands in relation to them, it’s time to look at how mastery of those skills can enable youth with disabilities to more successfully and confidently set goals for themselves.
Areas needing improvement can be turned into areas of strength if a person makes a conscious effort to address them and understands that this transformation will not happen overnight. Look over the results on the questionnaire and the areas that you agreed with the young person that he or she needs to work on. Then, work with him or her to develop three short-term goals for building his or her skills in these areas starting with the ones you rated as the highest priority. Read the example below before completing the activity.

Remember, the only goal the young person can not achieve is the one he or she does not attempt!

**Example:**
If you answered NO to Question #1 “Does the young person know what his or her strengths are in school?,” you could work with the young person on reflecting upon his or her strengths and encourage him or her to ask for input from others such as friends, parents, coaches, teachers, and employers. Together, make a list of the strengths mentioned by others and work with the young person to select and develop goals around three of these strengths.

For example, David has identified his strengths in the areas of math, computers, and art. He has also identified his area of need as explaining his disability. Now, keeping David’s strengths (e.g., math, computers, and art) in mind answer the following questions:

**Question 1:** How can he use his strengths to improve his ability to explain his disability?

**Answer #1:** David has difficulty describing his disability in writing or words (area of need), but he can use his artistic abilities to explain his disability through images. This would also show people that while he has a disability in some areas, he still excels in other areas such as art. In supporting him to use art to explain his disability, you could also expose him to other famous artists (e.g., Tolousse Latrec, Vincent Van Gogh, Frida Kahlo) with disabilities.

**Question #2:** What short-term goals would help him highlight his strengths?

**Answer #2:** You could support and encourage David to engage in extracurricular activities that match his strengths, such as the school newspaper or to volunteer to maintain the school website, or design sets for school plays.

**Question #3:** How can he use his strengths to reach his employment goals?

**Answer #3:** He can research which careers need people with strong skills in math, computers, and art. David may look into a graphic arts career field that interests him and highlights his skills. You could suggest that he look for a part-time job or internship in an art store or information technology firm.
**Question #4:** How can he use his strengths to reach his social goals?

**Answer #4:** David would like to broaden his circle of friends, but he finds it difficult to meet new people. You could encourage him to introduce himself to a few new people in his extracurricular activities and at his part-time job who have similar interests. One suggestion may be that he invite someone to an art exhibit.

**Question #5:** How can he use his strengths to reach his academic/educational goals?

**Answer #5:** David wants to improve his grades in English class this semester. You could encourage him to work on improving his grades by talking to his teacher about using his artistic or technical skills to supplement his writing assignments or using these skills to aid in writing his final assignment.

**Now, you try:**
List the strengths you and the young person identified through the questionnaire activity and discussions with others about his or her strengths.

Select three of these strengths that you can help him or her focus on in this activity.

1. ____________________________________________________________________________________

2. ____________________________________________________________________________________

3. ____________________________________________________________________________________

Identify the area of need that is first priority for short-term goal setting:

____________________________________________________________________________________

____________________________________________________________________________________

Focusing on these three strengths and the area of need that is first priority, answer the following questions:

**Question 1:** How can he or she use these strengths to improve in his or her area of need?

____________________________________________________________________________________

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____________________________________________________________________________________
Question #2: What short-term goals can I support him or her in developing to highlight these strengths?

____________________________________________________________________________________
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Question #3: How can he or she use these strengths to reach his or her employment goals?

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Question #4: How can he or she use these strengths to reach his or her social goals?

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Question #5: How can he or she use these strengths to reach his or her academic/educational goals?

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Question #6: What role can I play in helping this young person learn or become more informed about his or her disability and the importance of making informed decisions regarding disclosure?

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Question #7: How can I support his or her achievement of the 5 Self’s?

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Unit 3:

Disclosure...
What Is It and Why Is It So Important?

PURPOSE

The purpose of Unit 3 is to deepen your understanding of the concept of disclosure. We strongly suggest that you read the discussion section on page 3-2.

YOUR ROLE

Your role is to learn as much as you can about disclosure so that you can best support youth with disabilities in understanding what it is, why it’s important, and how it may differ in different environments or with different people. Your job is to be as supportive as possible and to provide the young person with tips, tools, and information so that he or she can make the most informed choice available.

TERMINOLOGY

You may know some of these words already, or you may have just heard them in passing. First, define these words as you understand them. Then check your definitions against the glossary located in the back of this workbook. The following terms are used in Unit 3:

<table>
<thead>
<tr>
<th>Disclosure</th>
<th>Confidential</th>
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A Workbook for Families, Educators, Youth Service Professionals, and Adult Allies who Care about Youth with Disabilities
Disclosure: 

__________________________________________________________________________
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Confidential: 

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DISCUSSION

When an individual tells someone something that was previously unknown, he or she is practicing disclosure. Disclosure comes from the word “disclose,” which means to open up, to reveal, or to tell. The term “disclosure” is used in different ways by different groups of people. For example, if an individual wants to buy a house and needs a loan, or if he or she needs a loan to attend college, he or she must disclose, or share his or her personal financial information with a loan officer at the bank. This information might include his or her income, savings and checking account information, any property he or she owns, any debt he or she has, and any other relevant financial information.

When an individual discloses, he or she is intentionally releasing personal information about him or herself for a specific purpose. Some personal information, such as one’s Social Security number, banking records, or medical records may be important to keep confidential. It is important to keep in mind that the decision to disclose is a personal one and should be helpful to the individual.

Remember that it is not essential that a person with a disability divulge all personal information about his or her disability. What is most important and helpful is to provide information about 1) how his or her disability affects his or her capacity to learn and perform effectively, and 2) the environment, supports, and services he or she will need in order to access, participate in, and excel in his or her job, studies, and community. The person with a disability must decide what and how much of this sensitive information is necessary to reveal in order to obtain the needed accommodations.

Here are some examples of disclosure:

- Michelle may disclose her disability to a potential employer who needs her to use technology that requires her using adaptive software.
- Evan may disclose his vision-related disability to new friends who have invited him to a concert because he needs accessible seating close to the stage in order to see.
• Aimee may disclose her use of a wheelchair to her internship coordinator if she needs accessible housing that’s close to public transportation.

• Roshanda might disclose her disability to her track coach because her math tutoring sessions overlap with track practice after school.

• If Joseph is applying for Social Security benefits, it is crucial for him to have his personal information related to his disability in order and ready to share with the benefits counselor.

When the young person in your life faces situations such as those described in the previous scenarios, he or she may need help locating and organizing his or her medical records, educational records, and recommendation letters. On the other hand, if the young person is applying for a disabled parking permit, he or she does not need to disclose all of his or her medical and disability-related paperwork; rather, he or she may only need to have a verification form completed by his or her medical doctor.

Let’s look at some examples in which an individual made the informed decision to disclose his or her disability in order to receive needed accommodations:

• Perez is deaf and will need an interpreter for a college interview.

• Joan, who is on the track team, has insulin-dependent diabetes and might need the help of her teammates if her blood sugar is low.

• Carlo, who has Attention Deficit Disorder (ADD), needs directions in written form because he misses steps when they are presented orally.

• Stephanie uses a wheelchair and has a personal assistant, who helps her with filing paperwork in vertical filing cabinets to facilitate her job as a chief financial officer.

• Colleen has schizophrenia, which is currently controlled with medication, and needs a private workspace or dividers in her work area to limit distractions and make her time at work more productive.

• Justin is autistic and needs a highly structured learning environment that focuses on his individual needs, which includes development of social skills, language, and self-help.

• Hideki has dwarfism and needs a lower locker at school.

It is important to keep in mind that the decision to disclose is a personal one...
Effective Disclosure

Effective disclosure occurs when a person is knowledgeable about his or her disability and is able to describe both his or her disability-related needs and his or her skills and abilities clearly. Answering the questions below will help you support the young person to effectively disclose his or her disability when he or she has decided disclosure is the best action.

Scenario: Jesse has chosen to share information about his disability with his mentor at the manufacturing plant. He has decided to tell his mentor, Joe, about his poor reading skills and difficulty comprehend the new equipment training manuals. Jesse believes it is essential he tell Joe because he will need to miss work to attend training sessions that demonstrate use of the new equipment and verbally present the new information.

Now, think about what it is about the young person in your life and his or her disability that he or she may need to reveal to the following people. Also reflect on why it would be important to reveal this information to this person. Record your reflections below. You may find it helpful to discuss with the young person what he or she sees as his or her needs in interactions with the following people as you reflect upon how you can help him or her.

Teacher/College professor: 

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Potential employer/supervisor: 

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Unit 4:

Weighing the Advantages and Disadvantages of Disclosure

PURPOSE

The purpose of Unit 4 is to help you understand how to assist a young person in determining the advantages and disadvantages of disclosure. By helping him or her to consider the pros and cons of all of the options available, you can support him or her in making an informed decision. Terminology provided in this unit will help you better understand this topic. We strongly suggest that you read the discussion section on page 4-2.

YOUR ROLE

Your role in this unit is to gain an understanding of the youth’s self-image, and fears and concerns about the advantages and disadvantages of disclosing his or her disability. In order to support him or her in making an informed choice, you need to be aware of the consequences of disability disclosure, both positive and negative.

TERMINOLOGY

You may know some of these words already, or you may have just heard them in passing. First, define these words as you understand them. Then, check your definitions against the glossary that is located in the back of this workbook. The following terms are used in Unit 4:
### DISCUSSION

Only the person with a disability can decide whether or not he or she wants to disclose his or her disability or any other sensitive information to others. Read what one high school student had to say about the issue of disclosing a disability:

“I used to be ashamed about my disability and the fact that I couldn’t read very well or very fast, but as I have gotten older, I know that I need to explain how I work and learn best to my boss. Now, I feel like I am a good employee.”

As with most important informed decisions a person will make during his or her lifetime, there are both advantages and disadvantages associated with the decision to disclose. On the one hand, disability disclosure can open up opportunities for a person with a disability to participate in activities that he or she may have avoided, or in which he or she have been unable to participate, and help him or her put into place a strong support system. On the other hand, it’s downright scary to tell someone something personal when there are no assurances that they will react positively to your news. When added onto the hormones, anxiety, and lack of confidence common in teenagers and young adults, this fear can be even more intimidating.

What follows is a summary of advantages...
and disadvantages to disclosure. This list is by no means exhaustive, but it may give you some good information to think about as you work with a young person with a disability. Remember, what may be a disadvantage in one setting or situation may be an advantage in another.

Advantages of disclosure:

- It allows a person with a disability to receive supports and reasonable accommodations so that he or she can pursue work, school, or community activities more effectively.
- It provides legal protection against discrimination as specified in the ADA and other related statutes.
- It reduces stress, since protecting a “secret” can take a lot of energy.
- It gives a person with a disability a clearer impression of what kinds of expectations people may have of him or her and his or her abilities.
- It ensures that he or she is getting what he or she needs (e.g., accommodation or medication) in order to be successful.
- It provides full freedom to examine and question health insurance and other benefits.
- It provides greater freedom to communicate should he or she face changes in his or her particular situation.
- It improves his or her self-image through self-advocacy.
- It allows him or her to involve other professionals (e.g., educators and employment service providers) in the learning of skills and the development of accommodations.
- It increases his or her comfort level.

Disadvantages of disclosure:

- It can cause him or her to relive bad past experiences that resulted in the loss of a job or negative responses from peers.
- It can lead to the experience of exclusion.
- It can cause him or her to become an object of curiosity.
- It can cause others to blame him or her if something doesn’t go right.
- It can cause others to treat him or her differently than others.
- It can bring up conflicting feelings about his or her self-image.
- It can cause others to view him or her as needy, not self-sufficient, or unable to perform on par with peers.
- It could cause others to overlook him or her for a job, team, group, or organization.
- It can be extremely difficult and embarrassing.

Use the lists above to coach the young man or woman in your life about advantages and disadvantages of disability disclosure. Consider how you felt the last time you heard a person with or without a disability disclose something very personal and sensitive in nature. Sharing both positive and negative examples with the young person will help him or her prepare for his or her own disclosure. Remember to emphasize that

- He or she makes the choice when, where,
Unit 4: The Advantages and Disadvantages of Disclosure

and to whom to disclose; and

- Disclosing is the only way to get the accommodations he or she needs in a particular school, work, or social setting.

Support the young man or woman in developing a personal philosophy statement about disclosure by encouraging him or her to answer the following questions: “What does it really mean to me to be a person with a disability and how does it affect my life?” Only the young person can answer that question, because even people with the same disability feel differently and experience things differently. Read below about one student’s philosophy on disclosure.

“My work mentor really convinced me that having a learning disability is nothing to be ashamed of. He made me realize that I’m not dumb, and I’m not stupid. I’ve learned that you must be an advocate for yourself, otherwise you get trampled. So, I go full force. It’s something I’ve always done in my life; just get behind everything 110%. A cliché, but it’s because with my disability I’ve always had to work harder, it seems, than everyone else.”

In the next unit, you will learn about how the law protects the young person if he or she chooses to disclose.
Read each scenario carefully. Discuss and list some of the advantages and disadvantages of disclosing the sensitive information in each scenario.

**Scenario for secondary education:** Liz is 13 years old and eager to get a babysitting job over the summer. She put flyers out all over the neighborhood and has gotten quite a few calls. One of the prospective clients she was talking to goes to church with Liz and her family. Liz’s mother mentioned to one of the families that Liz was hospitalized after a seizure when she was 10 years old, but has not had one since then. Liz participates in several in- and out-of-school activities and gets regular check-ups with her doctor. The news spread quickly and Liz is no longer getting phone calls about babysitting. How could Liz handle the situation? What are the advantages or disadvantages to this approach?

**Strategy:**

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Advantages:

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Disadvantages:

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Scenario for postsecondary education: Calvin is extremely shy but excited about starting college. He is registering for his first semester of classes and realizes that all freshmen are required to take public speaking. Calvin stutters severely when he speaks, especially around new people. Consider Calvin’s self-image and his concern about his stuttering. Would it be to Calvin’s advantage or disadvantage to disclose his disability to his potential professors, classmates, and roommates? What should his strategy be?

Strategy: ________________________________________________________________
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Advantages: ________________________________________________________________
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Disadvantages: ______________________________________________________________
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Scenario for social setting: Brandy has cerebral palsy and requires the use of a wheelchair. Brandy has been invited to a pool party at a friend’s house. Brandy cannot swim without help. If she goes to the pool party, someone will have to accompany her in the water, and all her friends will see. Think about the impact of Brandy’s disclosing her disability to her friends. What are some of the advantages or disadvantages of disclosure? How could Brandy handle the situation? What are the advantages or disadvantages to this approach?

Strategy: ________________________________________________________________
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Scenario for secondary education: Michael is 16 and has been diagnosed with bipolar disorder for much of his teenage years. He just started new medications and noticed that they made him sleepy in class, so he spoke with his mom about his concerns. His mom told him not to tell anyone because people would think he was crazy and then the state would try to take him away. As he’s getting ready for soccer season, Michael’s grades are starting to slip. He is worried about his next report card and that he’ll end up ineligible to play. What should Michael do? What are the advantages and disadvantages to this approach?

Strategy: ____________________________________________

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Advantages:  _______________________________________________________________________

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Disadvantages:  ___________________________________________________________________

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____________________________________________________________________________________
Scenario for employment: Kisha is fresh out of college and looking for a job. She has a vision impairment and uses a number of different pieces of software including a screen reader and a document reader. She has an interview coming up at a law firm that will require her to use the computer for a hands-on exercise and there’s little likelihood that the computer will have her software loaded. What should Kisha do? What are the advantages and disadvantages to this approach?

Strategy: 

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Advantages:

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Disadvantages:

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Unit 5: Rights and Responsibilities Under the Law

PURPOSE

The purpose of Unit 5 is twofold: (1) to provide an overview and increase understanding of how systems and protective laws change when a young person with a disability leaves high school and enters the “adult world;” and (2) to provide a basic overview of the Americans with Disabilities Act (ADA) and its importance in the post-school world. We strongly suggest that you read the discussion on page 5-4.

YOUR ROLE

Adults supporting youth with disabilities need to be aware of public policies pertaining to individuals with disabilities and the civil rights protections of people with disabilities as they move from school to adulthood. In order to best support a young person with a disability in making this transition, there are many pieces of legislation you need to be aware of, particularly the Individuals with Disabilities Education Act (IDEA) and ADA. As a young person begins exercising the 5 Self’s and becoming a stronger, more self-determined advocate, you can support him or her in gaining an understanding of the important role that these policies have in his or her life.
You may know some of these words already, or you may have just heard them in passing. First, define these words as you understand them. Then check your definitions against the glossary that is located in the back of this workbook. The following terms are used in Unit 5:

<table>
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<th>Accessible</th>
<th>Eligibility</th>
<th>Individual Plan for Employment</th>
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<td>Adult Services</td>
<td>Entitlement</td>
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<td>Compensatory Strategies</td>
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<td>Disability (under the ADA)</td>
<td>Hidden Disabilities</td>
<td>Individualized Education Program (IEP)</td>
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<td>Discrimination</td>
<td>Individualized Transition Plan</td>
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Accessible: 

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Adult Services: 

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Compensatory Strategies: 

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Disability (under the ADA): 

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Discrimination: 

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Eligibility: 

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Entitlement: 

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Free Appropriate Public Education (FAPE): 

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Hidden Disabilities: 

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Individualized Education Plan (IEP): 

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Individual Plan for Employment (IPE): 

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Summary of Performance (SOP): 

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Transition Plan: 

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Visible Disabilities: 

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Have you ever broken a bone, had a cast, or needed to use crutches, a brace, or a sling? What was it like for you? What kind of help did you receive from friends, family, and teachers? Maybe people opened doors for you, helped you copy down your homework, or provided you with extra time to complete assignments. Temporary conditions such as broken bones are short term and generally heal over time. A disability, on the other hand, is constant and life-long.

Some disabilities are visible (e.g., using a wheelchair or the service of a guide dog) which means they can be seen by others, while some disabilities are hidden (e.g., learning disabilities, Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder, epilepsy, depression, or bipolar disorder). Some people are born with disabilities while others acquire their disabilities later in life.

Believe it or not, the term “disability” is not easily defined. Disability is defined one way for students up through twelfth grade and in a different way for individuals in postsecondary education and the world of work.

**IDEA Definition of Disability:**

The Individuals with Disabilities Education Act (IDEA) defines “disability” for young people up through twelfth grade. Further, the IDEA identifies 13 categories of disability. These Federal categories help states to determine who is eligible for special education supports and services in public schools.

The IDEA recognizes these 13 categories of disability:


* Attention Deficit Disorder (ADD) or Attention Deficit Hyperactivity Disorder (ADHD) as a primary disability is often placed in the category of Other Health Impairment.

For more detail on the definition of each category, see [http://ericec.org/digests/e560.html](http://ericec.org/digests/e560.html).

Under IDEA, young people with disabilities are entitled to a **Free Appropriate Public Education (FAPE)**. This means that if a student is eligible to receive special education services, the school will provide any services, supports, and accommodations he or she
needs at no cost to the student and his or her family.

When a student is in elementary or secondary school, a team of people works on his or her behalf to make sure that he or she receives the most appropriate education. At least once a year, this team, including the student and his or her parents, meets to make sure that the student is showing progress and receiving the accommodations needed to be successful in his or her classes. An Individualized Education Program (IEP), a set of personal goals and objectives, is developed for the next school year based on agreements between school personnel and the family established during the IEP meeting. The student’s IEP should take into account what the student plans to do in his or her future following high school.

While in school, there is no need for a student to ask for accommodations because IDEA says the school must take responsibility for identifying and providing whatever services the student needs to receive an appropriate education. In other words, a student with a disability is not required to self-disclose his or her disability in order to qualify for the supports and services available; it is a matter of entitlement.

The IEP process is a unique opportunity for a young person with a disability to exercise those 5 Self’s mentioned earlier in the guide. You can support the young person in developing his or her self-advocacy and self-determination skills by urging him or her to participate in IEP meetings as early as possible. Even a student in elementary school should be supported in expressing what classes he or she likes, what accommodations are or are not working, what classes or experiences (e.g., service learning, clubs, after school programs, etc.) he or she would like to participate in, and what he or she might like to do in the future. Waiting until two years before graduation to involve the young person in transition planning is too late!

Under the entitlement focused laws that protect a person with a disability while he or she is in elementary and secondary school, the focus remains on his or her disability and what the best educational program should be based on his or her strengths and needs. The services provided to him or her may change over time depending on a lot of factors, including his or her progress and new federal policy initiatives; however, the process remains essentially the same from year to year. The young person meets every year with his or her family and school personnel to establish a plan for the next year.

Prior to exiting high school, the student, his or her family, and the rest of the IEP team begin working on the student’s individualized transition plan. As a result of the 2004 reauthorization of IDEA, schools are also now required to issue a Summary of Performance (SOP) for students transitioning from K-12. The SOP, which is to be developed in lieu of an exit IEP, describes the youth’s academic, cognitive, and functional levels of performance. It also includes recommendations on how to assist the youth in meeting his or her postsecondary goals including the use of assistive technology and
accommodations. Starting freshman year of high school, each of these areas is expanded upon to include the student’s present level of performance and the accommodations, modifications, and assistive technology that are essential in high school to assist the student in achieving progress.

The SOP is critical for students to have when exiting high school, even though the accommodations they may request and obtain in the post-IDEA world may be different. (Samples and templates of SOPs may be found at http://www.ahead.org.)

**ADA Definition of Disability:**

When a person with a disability graduates or exits from the public school system, the way that he or she is defined as a person with a disability changes because the laws that protect him or her and provide for the accommodations he or she may need to be successful in postsecondary institutions and/or in the workplace change. While IDEA is the law that served to protect him or her through high school, when he or she exits school and enters college, adult education, and the world of work, other laws such as the ADA, the Workforce Investment Act (WIA), and the Health Insurance Portability and Accountability Act offer protection.

A person qualifies as having a disability under the Americans with Disabilities Act (ADA) if they meet at least one of the following three conditions:

1. A physical or mental impairment that substantially limits one or more major life activities (e.g., such as walking, talking, seeing, reading, learning, working, etc.);

2. A record of such impairment (e.g., people with a history of cancer or mental illness);

or

3. Being regarded as having such an impairment such as a person with a disfiguring facial scar, or a person rumored to be HIV positive.

When a person with a disability exits high school, he or she moves from a system of entitlement to a system of eligibility. Once the person enters college, adult education, or the world of work, the only way he or she can receive the accommodations he or she needs is to ask for them. That is why it’s so important for a person with a disability to understand him or herself, and his or her disability, and to be able to communicate effectively his or her accommodation needs.

It is also important for people with disabilities to understand the laws that protect them in case they do decide to disclose their disability. The purpose of the ADA is to extend to people with disabilities civil rights protections similar to those already available to people on the basis of race, color, national origin, and religion through the Civil Rights Act of 1964.

Basically, the ADA prohibits discrimination on the basis of disability in five general areas:

- Private sector employment
- Activities of states and local governments
- Places of public accommodation
- Transportation
- Telecommunication services

Prior to the passage of the ADA in 1990, it was legal for businesses to discriminate against people with disabilities in these situations. The ADA was enacted because
people felt there needed to be a law that prohibits discrimination against people with disabilities. (For more details on ADA, see Appendix B.)

Now fast forward to high school graduation or exit. The adult world is a very different place than high school. The student leaves a system of entitlements and enters a system of eligibility. They must meet certain requirements to receive services of accommodation. It is at this time that the student and his or her family are faced with an array of adult service providers, postsecondary institutions, and others all of whom are asking one question: Does the young person meet the eligibility requirements of this program?

Of course, various programs may offer different services and have different eligibility requirements. It’s up to the young person, his or her family, and the caring adults in his or her life to work together to determine which services will be the most beneficial to him or her, and whether he or she is eligible for those programs. Once the youth graduates or exits high school, the student is no longer entitled to services and supports. Rather, he or she becomes eligible for adult services and supports based on his or her particular situation, his or her disability, and his or her ability and willingness to disclose necessary information.

For example, a young person with a disability who is looking for a job after high school can seek help from the vocational rehabilitation (VR) system in his or her community. Vocational rehabilitation services are intended to assist individuals with disabilities to obtain employment that is consistent with the individual’s strengths, resources, priorities, concerns, abilities, capabilities, interests, and informed choice. When the young person contacts VR, he or she will be asked to go through an eligibility screening process that requires disclosing information about his or her disability. Once the VR system verifies that the young person is eligible, a VR counselor will work with him or her to develop an Individual Plan for Employment (IPE). An IPE is a written agreement between the young person and the VR agency that describes the individual’s vocational goals, services and supports he or she needs to accomplish those goals, and how those services and supports will be provided or purchased. VR offers various forms of assistance, such as career assessments, vocational training, and assistive technology, but individuals with disabilities have to disclose their disability and meet the eligibility requirements to take advantage of them.

Remember that graduation or exit from high school doesn’t mean that the services and accommodations the young man or woman needed while in high school aren’t needed anymore. Lots of young people think that once they leave school their disability is unimportant or disappears. They haven’t figured out that the academic services and accommodations they received while in high school may be needed for life in different ways.

On the other hand, some students may have developed compensatory strategies to help them minimize certain troubles they were having while they were in high school. They may have a good handle on what they need to be successful in college or on the job. For example, a young adult who tends to forget information that is presented visually but can
remember information when it is presented orally could utilize a tape recorder during classes and conversations.

Keep in mind that once youth with disabilities leave high school and enter the system of eligibility, they are still entitled to protection against discrimination due to their disability. People with disabilities have certain rights that allow them to challenge decisions made concerning their eligibility.

One example of a law offering such protection is the non-discrimination clause of the Workforce Investment Act (WIA) Title I, Section 188. The non-discrimination clause, which is in place to protect individuals from discrimination, states that “no individual shall be excluded from participation in, denied the benefits of, subjected to discrimination under, or denied employment in the administration of or in connection with, any such program or activity because of race, color, religion, sex, national origin, age, disability, or political affiliation or belief.”

Another example is the Health Insurance Portability and Accountability Act (HIPAA). This act became law in 1996, and it protects individuals and families by allowing health insurance to continue despite changes in employment status or transition periods between jobs. In addition, HIPAA addresses the security and privacy of your health records. There are now rules and limits on who can look at and receive your health information. Some of the information that is protected includes the following:

- Information your doctors, nurses, or other health care professionals put in your medical record;
- Conversations your doctor has about your care or treatment with nurses and others;
- Information about you in your health insurer’s computer system; and
- Billing information about you at a health care facility.

In addition to laws, there are also programs that assist people with disabilities. An example is the Client Assistance Program (CAP). This service can assist and advocate for a person with a disability if he or she is having concerns or problems with state agencies, Vocational Rehabilitation (VR), the Commission for the Blind, or Independent Living Centers. CAP can provide assistance in several ways including:

- Informing and advising people with disabilities of benefits available under the Rehabilitation Act;
- Helping people with disabilities communicate their concerns to their counselor;
- Helping people with disabilities resolve their concerns if they disagree with a decision;
- Helping them understand the rules, regulations, and procedures of an agency; and
- Protecting their rights under the Federal Rehabilitation Act.

Additional information about some of the pieces of legislation discussed in Unit 5 and other legislation that may potentially affect a young person with a disability in the future is summarized in Appendix C in the back of this unit beginning on page 63.
The following activity is designed to help you work through how you perceive the young person’s disability affecting his or her school, work, and social life and how certain laws can protect his or her rights. Use these questions and prompts to begin thinking about these important issues.

1. Describe how you think his or her disability may affect his or her postsecondary education efforts.
   
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   ______________________________________________________________________
   
   ______________________________________________________________________

2. Describe how you think his or her disability may affect his or her work performance.
   
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3. Describe how you think his or her disability may affect his or her social life.
   
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Next, review information on the various laws in Appendix C and identify ways in which the laws can benefit and protect the young person.

Given the ways in which you anticipate the young person’s disability may affect his or her postsecondary education, work performance, and social life after high school, identify some ways each of the following laws may help him or her:
<table>
<thead>
<tr>
<th>Act</th>
<th>Details</th>
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<tbody>
<tr>
<td>Americans with Disabilities Act (ADA)</td>
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<tr>
<td>Assistive Technology Act</td>
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<tr>
<td>Developmental Disabilities Assistance and Bill of Rights Act</td>
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<tr>
<td>Individuals with Disabilities Education Act (IDEA)</td>
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<tr>
<td>Social Security Act (SSA)</td>
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<tr>
<td>Ticket to Work and Workforce Investment Improvement Act</td>
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<td>Medicaid Buy-In program</td>
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<tr>
<td>Workforce Investment Act (WIA), Title I, Section 188</td>
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<tr>
<td>WIA Title IV - Vocational Rehabilitation Act (including Section 504 &amp; 508):</td>
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<tr>
<td>Health Insurance Portability &amp; Accountability Act (HIPAA)</td>
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Recognizing Discrimination

Recognizing discrimination when it occurs is an important first step in confronting and eliminating it. Read the following examples and identify who is being discriminated against and in what way. Imagine you were the young person in each situation and reflect on how it would make you feel. How could you help a young person in this situation handle similar feelings? How would you advise the young person to handle the situation given what you know about the laws protecting the rights of individuals with disabilities?

Laura goes to a restaurant.

Laura goes with her friends to a pizza parlor. There are stairs to the entrance but no ramp. When Laura and her friends request assistance to get her wheelchair into the building, the manager refuses, citing liability risk.

Your reaction: ___________________________________________________________________
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John applies for a job.

John wants a job after school to earn money to buy his first car. He goes to a local sub shop and asks for an application. He has trouble completing the job application because of his learning disability in reading. He asks if the application could be read to him. The personnel director says, “No, you must complete the application on your own.”

Your reaction:
Aaliyah enrolls in a class.

Aaliyah has a learning disability. She is a freshman in college and is required to take a writing course. Her disability makes it very difficult to complete her writing assignments on time. When she discloses her disability to the professor, the professor suggests she withdraw from the class.

Your reaction: _____________________________________________________________
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Edward goes for job training.

Edward is deaf and wants to learn how to be a server in a restaurant. He enrolls in a training program. After doing all the exercises and filling out his paperwork the trainer pulls him aside and says “Yeah, I think this is a waste of your time and my time. No one is ever going to hire a deaf server.”

Your reaction: _____________________________________________________________
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________________________________________________________________________
In the beginning of this unit, we presented the different legal definitions of disability. Believe it or not, there are even more ways to define disability in the adult-services world. The definitions reflect “eligibility criteria” such as a person’s financial situation, the severity of his or her disability, and his or her age, among other characteristics. In order to be eligible for adult services, he or she needs to meet the eligibility criteria established for each specific service being requested. In this activity, you will support the young man or young woman with a disability in your life in exploring his or her eligibility for the services that might be beneficial. First, create a list of adult service providers in your community. Write down 10 providers in your community — you may or may not fill in all 10 lines provided below. Second, choose three services the young person is most likely to need as an adult and research the specific eligibility criteria associated with the service. Use the following resources and any others you think of to obtain this information: websites, telephone calls, letters, and email. Some suggested online sources for locating adult service agencies are listed in Appendix D. Keep the information you gather for future reference and share it with the young person.

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<tr>
<th>Agency #1:</th>
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<tr>
<td>Contact person:</td>
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<tr>
<td>Telephone and email:</td>
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<td>Eligibility criteria:</td>
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<tr>
<td>How to apply for services:</td>
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<tr>
<th>Agency #2</th>
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<tr>
<td>Contact person:</td>
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<tr>
<td>Telephone and email:</td>
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<tr>
<td>Eligibility criteria:</td>
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<td>How to apply for services:</td>
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<th>Agency #3:</th>
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<td>Contact person:</td>
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<tr>
<td>Telephone and email:</td>
<td></td>
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<tr>
<td>Eligibility criteria:</td>
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<td>How to apply for services:</td>
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Appendix B:

Basic Facts About the Americans with Disabilities Act

Title I – Employment

- Employers may not discriminate against an individual with a disability in hiring or promotion if the person is otherwise qualified for the job.
- Employers can ask about one’s ability to perform a job, but prior to offering a job they cannot inquire if someone has a disability or require medical examinations.
- Employers cannot use tests that tend to screen out people with disabilities unless the tests measure job-related skills.
- Employers need to provide “reasonable accommodation” to individuals with disabilities. This includes steps such as job restructuring and modification of equipment.
- Employers do not need to provide accommodations that impose an “undue hardship” on business operations.
- Who needs to comply:
  ~Private employers with 15 or more employees.
  ~State and local government employers, regardless of how many employees they have.

Title II – State and Local Governments

- State and local governments may not discriminate against qualified individuals with disabilities.
- State and local government agencies must make reasonable modifications to their policies and procedures to allow equal opportunities for individuals with disabilities to participate.
- All government facilities, services, and communications must be accessible consistent with the requirements of Section 504 of the Rehabilitation Act of 1973.
- All new construction must be accessible.
- New public transit buses must be accessible to individuals with disabilities.
- Transit authorities must provide comparable paratransit or other special transportation services to individuals with disabilities who cannot use fixed route bus services, unless an undue burden would result.
- Existing rail systems must have one accessible car per train.
- New rail cars must be accessible.
- New bus and train stations must be accessible.
- Key stations in rapid light and commuter rail systems must be made accessible by July 26, 1993, with
extensions up to 20 years for commuter rail (30 years for rapid and light rail).

• All existing Amtrak stations must be accessible by July 26, 2010.

**Title III – Public Accommodations**

• Private businesses such as restaurants, hotels, banks, and retail stores may not discriminate against individuals with disabilities.

• Auxiliary aids and services must be provided to ensure effective communications with individuals with vision or hearing impairments, unless an undue burden would result.

• Physical barriers in existing facilities must be removed, if removal is readily achievable. If removal is not readily achievable, alternative methods of providing the services must be offered, if they are readily achievable.

• All new construction and alterations of facilities must be accessible.

**Title IV – Telecommunications**

• Companies offering telephone service to the general public must offer telephone relay services to individuals who use telecommunications devices for the deaf (TDDs) or similar devices.

• All television public service announcements produced or funded in whole or in part by the federal government must include closed captioning.

**Title V – Miscellaneous Provisions**

• Title V includes information regarding the ADA’s relationship with other federal and state laws such as the Rehabilitation Act of 1973.

• Retaliation and coercion are prohibited.

• The U.S. Congress and the agencies of the federal legislative branch are covered; discrimination against individuals with disabilities is prohibited in employment and other programs.
## Appendix C

### Summary of Legislation

<table>
<thead>
<tr>
<th>Legislation</th>
<th>Summary</th>
<th>Resource</th>
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<tr>
<td><strong>Assistive Technology (AT) Act</strong></td>
<td>The AT Act requires states and territories to conduct activities related to public awareness, interagency coordination, technical assistance, and training and outreach to promote information about and access to assistive technology devices and services.</td>
<td><a href="http://www.section508.gov/docs/AT1998.html">http://www.section508.gov/docs/AT1998.html</a></td>
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<td></td>
<td>The AT Act also authorizes the Assistive Technology Alternate Financing Program to assist people with disabilities in accessing the technology that they need.</td>
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<tr>
<td><strong>Developmental Disabilities Assistance and Bill of Rights Act (DD Act)</strong></td>
<td>The DD Act requires that people with developmental disabilities and their families receive the services and supports they need and participate in the planning and designing of those services.</td>
<td><a href="http://www.acf.hhs.gov/programs/add/DDACT2.html">http://www.acf.hhs.gov/programs/add/DDACT2.html</a></td>
</tr>
<tr>
<td><strong>Individuals with Disabilities Education Act (IDEA)</strong></td>
<td>The IDEA guarantees youth with disabilities free and appropriate public education. Individuals are entitled to an education and related services.</td>
<td><a href="http://www.ed.gov/offices/OSERS/Policy/IDEA/the_law.html">http://www.ed.gov/offices/OSERS/Policy/IDEA/the_law.html</a></td>
</tr>
<tr>
<td></td>
<td>Services detailed in IDEA include transition services and planning, individualized education programs, early intervention services, due process provisions, disciplinary services, and alternative education programs.</td>
<td></td>
</tr>
<tr>
<td><strong>Health Insurance Portability and Accountability Act (HIPAA)</strong></td>
<td>HIPAA safeguards a person’s rights regarding their personal health information and sets limits as to who can access this information.</td>
<td><a href="http://www.hhs.gov/ocr/hipaa/">http://www.hhs.gov/ocr/hipaa/</a></td>
</tr>
<tr>
<td><strong>Social Security</strong></td>
<td>Supplemental Security Income (SSI) is a federal income supplement program designed to help aged, blind, and people with disabilities with limited income.</td>
<td><a href="http://www.ssa.gov">http://www.ssa.gov</a></td>
</tr>
<tr>
<td></td>
<td>The Student-Earned Income Exclusion supports the ability of transition-aged youth to work and have earnings through work-based learning programs that are integrated into educational programs.</td>
<td><a href="http://www.ssa.gov/OACT/COLA/studentEIE.html">http://www.ssa.gov/OACT/COLA/studentEIE.html</a></td>
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<tr>
<td>Legislation</td>
<td>Summary</td>
<td>Resource</td>
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<tr>
<td><strong>Social Security (continued)</strong></td>
<td>A Plan for Achieving Self Support (PASS) allows a person with a disability to set aside income for a given period of time to achieve an education or employment goal.</td>
<td><a href="http://www.ssa.gov/disabilityresearch/wi/pass.htm">http://www.ssa.gov/disabilityresearch/wi/pass.htm</a></td>
</tr>
<tr>
<td><strong>Ticket to Work and Workforce Investment Improvement Act (TWWIIA)</strong></td>
<td>The TWWIIA program offers SSA disability beneficiaries greater choice in obtaining the services they need to help them go to work and attain their employment goals.</td>
<td><a href="http://www.yourtickettowork.com/">http://www.yourtickettowork.com/</a></td>
</tr>
<tr>
<td><strong>Ticket to Work</strong></td>
<td>provides disability beneficiaries with a Ticket they may use to obtain the services and jobs they need from organizations called Employment Networks (ENs).</td>
<td><a href="http://www.yourtickettowork.com/">http://www.yourtickettowork.com/</a></td>
</tr>
<tr>
<td><strong>Medicaid Buy In Programs</strong></td>
<td>allow adults with disabilities to earn more than would otherwise be possible and still have Medicaid coverage.</td>
<td><a href="http://www.cms.hhs.gov/TWWIIA/07_Buyln.asp#TopOfPage">http://www.cms.hhs.gov/TWWIIA/07_Buyln.asp#TopOfPage</a></td>
</tr>
<tr>
<td><strong>Workforce Investment Act (WIA) and the Vocational Rehabilitation Act</strong></td>
<td>The WIA provides for coordinated, effective, and customer-focused workforce development and employment services to be delivered through One-Stop Career Centers.</td>
<td><a href="http://www.doleta.gov/regs/statutes/wialaw.txt">http://www.doleta.gov/regs/statutes/wialaw.txt</a></td>
</tr>
<tr>
<td><strong>Title I of WIA</strong></td>
<td>provides for services to youth, adults, and dislocated workers. The youth provisions of Title I of WIA require states and localities to provide a comprehensive workforce preparation system that reflects the developmental needs of youth.</td>
<td><a href="http://www.doleta.gov/regs/statutes/wialaw.txt">http://www.doleta.gov/regs/statutes/wialaw.txt</a></td>
</tr>
<tr>
<td><strong>Section 188 of Title I</strong></td>
<td>makes it illegal to discriminate against people with disabilities in employment and training programs, services, and activities receiving funds under WIA.</td>
<td><a href="http://www.dol.gov/oasam/programs/crc/section188.htm">http://www.dol.gov/oasam/programs/crc/section188.htm</a></td>
</tr>
<tr>
<td><strong>Title IV of WIA</strong></td>
<td>contains the entire Rehabilitation Act, comprised of the vocational rehabilitation program as well as the supported employment and independent living programs.</td>
<td><a href="http://www.ed.gov/about/offices/list/osers/rsa/index.html">http://www.ed.gov/about/offices/list/osers/rsa/index.html</a></td>
</tr>
<tr>
<td><strong>Section 504 of the Rehabilitation Act</strong></td>
<td>prohibits discrimination based on disability in federally funded and federally conducted programs or activities in the United States.</td>
<td><a href="http://www.section508.gov">http://www.section508.gov</a></td>
</tr>
<tr>
<td><strong>Section 508 of the Rehabilitation Act</strong></td>
<td>requires federal agencies to assure the accessibility and usability of their electronic and information technology.</td>
<td><a href="http://www.Section508.gov">http://www.Section508.gov</a></td>
</tr>
<tr>
<td><strong>Vocational Rehabilitation</strong></td>
<td>assists individuals with disabilities who are pursuing meaningful careers through local job searches and awareness of self-employment and telecommuting opportunities.</td>
<td></td>
</tr>
<tr>
<td><strong>Independent Living Centers</strong></td>
<td>are community-based organizations run by and for people with disabilities, which offer systems advocacy, individual advocacy, peer counseling, information and referral, and independent living skills training.</td>
<td><a href="http://www.ilusa.com/links/ilcenters.htm">http://www.ilusa.com/links/ilcenters.htm</a></td>
</tr>
</tbody>
</table>
Appendix D:

Suggested Websites for Locating Local Services

To search for local services for individuals with disabilities ranging from housing to employment assistance, go to http://www.Disability.gov/ and use the “Information by State” feature to find links to a range of service agencies located in your state. Once you select a search topic for your state (such as employment), you can view a list of websites for agencies and organizations in your state. By visiting the state specific websites, you should be able to find directories of county or city agencies that serve individuals in your local community.

To locate the nearest Workforce Services One-Stop Center, you can use America’s Service Locator at: http://www.service locator.org/.

To locate vocational rehabilitation service providers in your state, you can use the list of state agencies provided by the U.S. Department of Education at: http://wdcrobcolp01.ed.gov/Programs/EROD/org_list.cfm?category_ID=SVR.

To locate the nearest Center for Independent Living, you can use the online directory at: http://www.ilru.org/html/publications/directory/index.html

To locate the nearest Social Security Administration Office, you can use the field office locator online at: https://secure.ssa.gov/apps6z/FOLO/fo001.jsp. To find service provider agencies by state, use the following state-by-state directory: https://secure.ssa.gov/apps10/oesp/providers.nsf/bystate.

To find state agencies that focus on education transition support and services for youth entering adulthood, you can use the search engine provided by the National Center on Secondary Education and Transition at: http://www.ncset.org/stateresources/default.asp, or the Resource Map provided by the National Secondary Transition Technical Assistance Center at: http://www.nsttac.org/transitionstates/map.aspx.

It is also important to note what agencies or organizations provide legal representation and advocacy services to individuals with disabilities. The National Disability Rights Network's provides information on the Protection and Advocacy (P&A) System and Client Assistance Program (CAP) for each state at: http://www.napas.org/aboutus/PA_CAP.htm.
The purpose of Unit 6 is to introduce you to the concept of accommodations and to help you understand how to support young people with disabilities in identifying the accommodations they may need. We strongly suggest that you read the discussion on page 6-2.

When it comes to accommodations, your role in supporting a young person with a disability is to first help him or her understand what accommodations could he or she could use to learn, work, and participate fully and effectively in various settings. Second, your role is to help the young person find, request, secure, and evaluate accommodations that he or she has decided to use.

You may know some of these words already, or you may have just heard them in passing. First, define these words as you understand them. Then check your definitions against the glossary that is located in the back of this workbook. The following terms are used in Unit 6:

- **Barrier**
- **Modification**
- **Reasonable Accommodation**
- **Universal Design for Learning**
An accommodation is essentially any strategy that gets rid of or lessens the effect of a specific barrier. A barrier is an obstacle that may exist in school, at the workplace, in the community, or in your own home. An accommodation is any change or adjustment to an environment that makes it possible for an individual with a disability to enjoy an equal opportunity. Accommodations are used to help individuals with disabilities learn or demonstrate what they have learned; work as independently and efficiently as possible; and live comfortably within their communities and home, among other things. Sometimes accommodations can be modifications to existing equipment or materials to make them usable for people with disabilities (such as lowering a countertop for a register at a store, or changing the software on a computer to read school assignments aloud.) Modifications are alterations to an object, environment, or activity that results in increased usability. This is a reasonable accommodation and is protected by the ADA. Reasonable accommodations like adaptive software or barrier removal/adjustment allow a person with a disability to participate in the application process for a job or college or perform the essential functions of a particular job. Accommodations allow persons with disabilities to enjoy the benefits and privileges of employment and education to the same extent as individuals without disabilities.
Many times students with disabilities may be hesitant to try accommodations. They fear that others will perceive them as receiving special treatment or an unfair advantage. However, it’s important to advise them that accommodations are only intended to level the playing field. They are NOT intended to justify or compensate for a lack of knowledge, skills, or abilities necessary to succeed. Therefore, whenever possible, accommodations should be based on the use and further development of existing skills and capabilities.

One easy way to think about reasonable accommodations is to think of them in three basic categories:

1. Changes to facilities and equipment such as putting in ramps and parking spaces, making materials available in large print, or providing low- and high-tech assistive technology;

2. The provision of special services such as sign language interpreters or qualified readers; and

3. Creative thinking and problem solving!

There are many types of accommodations, including but not limited to the following:

- Educational accommodations;
- Workplace accommodations; and
- Community accessibility that serves to accommodate.

Some common examples of these various types of accommodations available to people with disabilities are listed below:

**Educational Accommodations**
- Accessible classrooms
- Modified instruction (e.g., use of small groups)
- Modified curricula (e.g., different learning outcomes or different materials from those for other students)
- Modified class schedules (e.g., block schedules)
- Providing supervised breaks or allowing extra response and processing time during testing sessions, and administering the test at the best time for the individual
- Providing special seating in a general education classroom (e.g., seating in the front of the room or in a study carrel), a small group setting, or special education support staff
- Providing large print materials, Braille materials, calculators, computers with spelling and grammar checkers, and electronic dictionaries
- Providing written copies of orally presented materials found in examiner’s manual, closed-captioning of video materials, or sign language interpreters
- Allowing individuals to answer by pointing rather than marking in a test booklet, by dictating responses to examiners for verbatim transcription, or by responding to an interpreter for transcription
- Universal Design for Learning (see definition on A-5)
Workplace Accommodations
- Changing an employee’s workstation arrangement (e.g., adjusting the lighting, raising up a desk on blocks)
- Modifying equipment or devices (e.g., computer software)
- Reassigning non-essential functions through job restructuring
- Providing qualified readers and interpreters
- Providing part-time or modified work schedules
- Telecommuting options
- Job Coaches
- Personal assistance services
- Adjusting or modifying examinations, training materials, and policies

Community Accessibility
- Providing ramps and reserved parking spaces to increase physical accessibility
- Providing assistive technology (e.g., readers, calculators, spell checkers, or communication devices)
- Providing interpreters
- Providing accessible bathrooms
- Providing accessible drinking fountains
- Providing accessible equipment (e.g., computers, desks, or copiers)
- Providing wide aisles and doorways

Another approach to meeting the needs of students with disabilities is called Universal Design for Learning. **Universal Design for Learning (UDL)** is an approach that addresses and redresses the primary barrier to making expert learners of all students: inflexible, one-size-fits-all curricula that raise unintentional barriers to learning. Learners with disabilities are most vulnerable to such barriers, but many students without disabilities, such as Limited English Proficiency (LEP) individuals, also find that curricula are poorly designed to meet their learning needs (National Center on Universal Design for Learning, 2009). More information on Universal Design can be found at the National Center on Universal Design for Learning’s website, http://www.udlcenter.org/.
The Job Accommodation Network (JAN)

The Job Accommodation Network (JAN) is a free service funded by the Office of Disability Employment Policy (ODEP), at the U.S. Department of Labor. JAN provides information about disability and accommodations, and receives questions concerning students with disabilities in classroom environments such as public schools, colleges, technical schools, continuing education, internships, employment, and about adults with disabilities.

To begin this activity, log on to the JAN website at http://www.askjan.org. Click “Individuals with Disabilities” on the left-hand toolbar. Take some time to explore what information and resources JAN has to offer. Make a list of those that you find particularly useful. If you do not have access to the World Wide Web, there is a toll-free phone number that you can call. Someone will be able to answer your questions and send you information. The phone number for JAN is 1-800-JAN-7234 V/TTY.

Next, use JAN’s Searchable Online Accommodation Resource (SOAR) to research ideas about accommodations both on the job and in school. Make a list of those accommodations that the youth with disabilities in your life currently uses, and those he or she might be interested in trying.

Accommodations in use: 

________________________________________________________________
________________________________________________________________
________________________________________________________________
________________________________________________________________

Accommodations to try: 

________________________________________________________________
________________________________________________________________
________________________________________________________________
________________________________________________________________

**ACTIVITY**

**Situations and Solutions at School and at Work**

Review the accommodation examples below. Your job is to figure out the obstacle (or barrier) for each young person. Use your creativity, the JAN website, and the broad categories of accommodations presented previously to create a list of possible accommodation solutions. Share and discuss your ideas for possible accommodations with the young person and find out what solutions he or she would propose in such a situation.

**Situation #1:** A student with muscular dystrophy is taking an SAT prep class at night. He has trouble filling in the bubbles on the answer sheets during practice drills.

Potential accommodation solutions:

____________________________________________________________________________________

____________________________________________________________________________________

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**Situation #2:** A teenager is intimidated about applying for a job at the local mall because her wheelchair will not fit between many of the clothes aisles in the major department stores.

Potential accommodation solutions:

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Situation #3: A student with dyslexia is taking a literature class. He reads slower and with more difficulty than the other students. Every student is required to read aloud from the texts in class.

Potential accommodation solutions: ____________________________________________________________

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Situation #4: A young man interning for graphic artist at a small employer is deaf and needs to be alerted to the employer’s audible emergency alarm system.

Potential accommodation solutions: __________________________________________________________

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Situation #5: A student with depression is interning for her school newspaper. When she has a depressive episode she misses article deadlines.

Potential accommodation solutions: __________________________________________________________

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| Situation #6: A chef student with dyscalculia, which is a math learning disability, is having trouble measuring the ingredients for recipes. |
| Potential accommodation solutions: |
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| |

| Situation #7: A recent college graduate with social anxiety, hired at a corporation, is overcome with anxiety about speaking in front of his co-workers at business meetings. |
| Potential accommodation solutions: |
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| Situation #8: A student in medical school who has a reading disability is also a poor speller. She has difficulty reading and spelling the medical terminology and prescription names. |
| Potential accommodation solutions: |
| |
| |
| |
| |
| |
The purpose of Unit 7 is to give you information that you can use to assist the young person with a disability in making decisions about disclosure to get reasonable accommodations in postsecondary education settings. Postsecondary education settings include universities and four-year colleges, community colleges, technical colleges, and career and technical schools. In addition, this unit clearly answers five specific disclosure questions: why, when, what, to whom, and how to disclose a disability in postsecondary settings. We strongly suggest that you read the discussion focusing on “why to disclose” on page 7-3.

As a young person moves from high school to adulthood, remember that your role is to prepare him or her the best you can to feel empowered and secure in disclosing his or her disability to get the accommodations he or she needs. It is not to disclose for him or her. In fact, once he or she reaches age 18, most service providers will not even talk to you about the young person or his or her disability related needs. Remember, once the youth leaves high school, the responsibility and power to disclose is his or hers. Your job is to be as supportive as possible and to provide him or her with tips, tools, and information. The aim is to help him or her make the most informed choice possible and to disclose effectively if he or she decides to do so.
You may know some of these words already, or you may have just heard them in passing. First, define these words as you understand them. Then check your definitions against the glossary that is located in the back of this workbook. The following terms are used in Unit 7:

<table>
<thead>
<tr>
<th>Access</th>
<th>Disability support services (DSS)</th>
<th>Responsibility</th>
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</thead>
<tbody>
<tr>
<td>Assistive technology</td>
<td>Disclosure script</td>
<td>Rights</td>
</tr>
<tr>
<td>Access:</td>
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<td>Assistive Technology:</td>
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<td>Postsecondary:</td>
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<td>Responsibility:</td>
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<tr>
<td>Rights:</td>
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The process of choosing a postsecondary institution is quite challenging. There are many decisions a young person with a disability will need to make: where to study, what to study, how to study, whether to attend full-time or part-time, whether to live at home or on campus, and whether to commute from a distance or enroll in online study are just a few.

Youth with disabilities must also consider the supports and services that they may need to be successful in the postsecondary setting of their choice. Once a young person with a disability is enrolled at a postsecondary institution, he or she can request services and support from the office or staff at the institution that oversees disability support services. Many colleges and universities have an office called the Disability Support Services (DSS) office. At other institutions, disability support services may be the responsibility of the student counseling office or a Section 504 officer.

Remember, accommodations at the postsecondary level (after he or she exits high school) need only be provided when a student discloses his or her disability and requests accommodations. Instructors and other staff are not required to provide accommodations to students who have chosen not to disclose their disabilities.

Learning to disclose disability-related needs effectively and to develop an accommodation plan are extremely valuable skills for a young person with a disability. Effective disclosure involves sharing information regarding one’s disability-related needs and also providing creative, practical suggestions for accommodations. Open communication with instructors and disability support services staff can facilitate the process of evaluating the effectiveness of accommodations, and of making changes when efforts are not working.

This is also where that the Summary of Performance (SOP) mentioned earlier comes into play. Work with the young person to understand the importance of the SOP and how it can be used as a tool to help him or her articulate his or her disability related and accommodations needs as he or she moves on to postsecondary education. Remember, the school he or she is transitioning to may not have the exact same accommodations available. Nonetheless, the SOP can be used as a guide to what has worked before to open up a conversation about what can work in the future.

Good planning is always important, but early planning is essential. The sooner the young person starts understanding, planning for, and taking charge of his or her needs, the
more confident and effective he or she will be in each new setting and situation. During high school is an ideal time for young people to be thinking about and planning for what they want and need in postsecondary settings.

Some reasons why people may choose to disclose their disabilities in a postsecondary setting include, but are not limited to, the following:

• To obtain information about available supports and services;

• To identify adjustments necessary to the study environment;

• To learn about academic requirements and practical components of a chosen course of study, in addition to possible professional requirements;

• To receive any necessary assistance with the transition from high school to postsecondary education;

• To ensure that disability support service professionals provide any needed training or awareness for faculty members and other staff to help students with disabilities receive the best accommodations; and

• To ensure that faculty members are familiar with and implement the accommodations students require to be successful in their classes.

Remember that it is not essential to divulge specific personal information about a disability. What is most important and helpful is for the student to provide information about:

1. How disability affects his or her capacity to learn and study effectively, and

2. The environment, supports, and services he or she needs in order to access, participate in, and excel in his or her area of study.

Although confidentiality is protected under both the ADA and Section 504, it is up to the student with a disability to determine his or her own personal privacy boundaries. He or she must decide what and how much information is necessary to reveal in order to obtain the needed accommodations.

WHEN to disclose in postsecondary education

It is important to think about the most appropriate time and place in which to disclose a disability in the postsecondary setting. The timing of the disclosure is important and can potentially have an impact on how youth with disabilities are perceived by others and what accommodations can be provided. There are four options for “when” to disclose:

Prior to enrollment

Before enrolling in classes, students usually have a chance to meet with instructors, or disability student services staff. At this time, a student with disability should be prepared to disclose his or her disability and start planning for needed accommodations. This should include discussing accommodation strategies that will work for him or her and the instructors.
At the time of enrollment

It is usually recommended that a student with a disability inform his or her instructors of any needed accommodations at the beginning of a semester or class, or as soon as a disability starts interfering with his or her progress in class.

During their course of study

If a student waits to disclose his or her disability until after classes have started, there may be additional considerations. For example, if a student decides to wait to disclose his or her disability and makes a request for accommodations the day before an exam (an example of poor timing), the disclosure may be stressful and the accommodation may be difficult or impossible to arrange on short notice.

If, on the other hand, a student approaches the instructor before the first class session to voice his or her concerns and proposes potential accommodation strategies, then accommodations can be arranged in an organized, thorough manner with sufficient time to implement them. Everyone is more comfortable with this arrangement.

Never

It is important to remember that if no accommodations are needed, or if a student has made a decision to accommodate his or her potential needs personally (e.g., by using a spell-check feature for English papers) there is no need for the youth to disclose his or her disability.

WHAT information to disclose in a postsecondary education setting

Remember that preparation is essential when planning to disclose a disability. Don’t forget that it is unnecessary to disclose very detailed medical or personal information.

You can help a young person with a disability to think about disclosing his or her disability concisely to disability support services staff, instructors, or others in the academic setting by limiting disclosure to the following:

- General information about his or her disability;
- Why he or she chose to disclose his or her disability (e.g., its impact on his or her academic performance);
- The type of academic accommodations that have worked for him or her in the past in high school;
- The type of academic accommodations he or she anticipates needing in the postsecondary setting; and
- How his or her disability and other life experiences can affect his or her course of study positively.

TIP: Support the student in focusing the disclosure conversation on his or her academic abilities, not on his or her disability.

To WHOM to disclose in postsecondary education

People with disabilities only need to disclose their disability to those individuals who need to know. Sometimes, the person they choose to disclose their disability will be determined by when they choose to disclose.
In supporting a youth with a disability, you may want to work with him or her to practice or rehearse disclosing his or her disability in different settings in the academic environment. The following list includes examples of people that a young person with a disability may choose to disclose his or her disability to at different times.

- Prior to enrollment, a student might choose to disclose to the disability support services staff, directly to instructors, or to an admissions officer.

- At the time of enrollment, it might be helpful to disclose directly on the application form or contact the disability support services staff.

- During a student’s course of study, he or she might choose to contact his or her academic advisor or counselor, instructor, or disability support services staff.

- When in doubt, contact the trained professionals who provide disability support services for guidance.

Throughout the process of disclosure and accommodations development, it is very important that students with disabilities work closely and cooperatively with individuals such as instructors, counselors, disability support services staff, and higher education administrators, who can provide the supports and services. When requesting accommodations, advise students to try to be positive and assertive rather than aggressive and confrontational. They will really “earn more with honey than vinegar.” This is especially true if something comes up at the last minute.

There are differences between assertive and aggressive communication and behavior. Assertive communication and behavior is preferable. Being assertive means that youth (a) stand up for their personal rights; (b) express their thoughts, feelings, and beliefs in a direct, honest, and appropriate way; (c) show respect for themselves and others; and (d) leave room for compromise. It is important for students to maintain good eye contact, express themselves clearly, stay on topic, and avoid apologizing or losing their temper.

Remember that it’s important for students to have a private, confidential, comfortable place to disclose, and to allow enough time for them to discuss the impact of their disabilities. The person(s) he or she is disclosing to may have questions, suggestions, or concerns that may require extra time for discussion.
### Rights and Responsibilities

Adapted from [http://sites.uws.edu.au/rdlo/disclosure/education/prior.htm](http://sites.uws.edu.au/rdlo/disclosure/education/prior.htm).

We’ve talked a great deal about the rights afforded people with disabilities. It is also important to understand that people with disabilities also have significant responsibilities to themselves, their instructors, and the disability support services staff. Some of these rights and responsibilities are outlined in the chart below:

<table>
<thead>
<tr>
<th><strong>Students with disabilities have the RIGHT to:</strong></th>
<th><strong>Students with disabilities have the RESPONSIBILITY to:</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Be treated fairly and in a non-discriminatory fashion.</td>
<td>• Investigate and fully understand the academic and practical requirements of their chosen course of study, including determining that this option matches their skills and abilities.</td>
</tr>
<tr>
<td>• Discuss their academic needs, supports, and accommodations in a non-judgmental setting.</td>
<td>• Recognize that disclosing on an application form or prior to enrollment does not eliminate their responsibility to contact disability support services after they are enrolled or contact their professors for any needed accommodations.</td>
</tr>
<tr>
<td>• Have information about their disability treated confidentially and respectfully.</td>
<td>• Find out about options for accessing the institution of their choice.</td>
</tr>
<tr>
<td>• Know what happens to personal information they choose to share with counselors, faculty, or staff.</td>
<td>• Advise faculty and staff in a timely manner of their needs in relation to their disability, including accommodation, support, and information.</td>
</tr>
<tr>
<td>• Work collaboratively with staff to identify necessary supports for their success.</td>
<td>• Understand that disability support services staff or faculty may not be able to address their needs effectively if they do not disclose them in a timely manner.</td>
</tr>
<tr>
<td>• Obtain information about disability support services as well as physical and programmatic access at the institution of their choosing.</td>
<td>• Be self-determined and practical.</td>
</tr>
<tr>
<td>• Be self-determined and practical.</td>
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</tbody>
</table>
**Exploring Disability Support Services**

Take a field trip with the young man or young woman with a disability in your life to visit a local community college or university, and make an appointment with the counseling or disability support services office to find out what supports and services are available. Prepare the young person you are working with to discuss his or her accommodation needs, including what supports have typically helped him or her in the past. There are counselors available to discuss specific issues with you, answer your questions, and offer support. In addition, tutoring and assistive technology supports might be available.

To ensure the young person knows which supports and services are available at this location, make a note of the name of the person you met with and his or her contact information (e.g., address, telephone number, and email). You or the young person may want to contact this person again or send a thank-you note following your visit.

Use the following guidance on campus visits and role plays to help the young person prepare for the visit.


**Before You Arrive on Campus**

- Work with the student to talk about his or her strengths and opportunities, disability, and short-term and long-term goals.
- Develop a list of questions usually not covered in the college catalog.
- Role-play some potential interviews with the student.
- Practice answers to typical questions until they sound clear and comfortable.
- Prepare to use this visit as an opportunity to help determine the appropriateness of the college as a possible final choice.
- Prepare to take notes for future reference.

ACTIVITY

_______________________________________________________________________________

_______________________________________________________________________________

_______________________________________________________________________________

_______________________________________________________________________________
**Role Play #1:** Here are some questions that you can use to practice with youth with disabilities. You play the disability support services staff and have the youth practice his or her responses.

- What are the requirements for admission? Are they flexible?
- How many students with disabilities are on campus? Is there a disabled student union?
- What services does the college typically provide to students with disabilities? Who provides them?
- How long are services provided?
- Are remedial courses available on campus?
- Does the college provide remediation or support one-on-one or in a group setting?
- What kinds of academic adjustments, accommodations, and auxiliary aids and services does the college have available to students with disabilities?
- Will I be able to check out equipment and use it in my classes?
- Is free tutoring available on campus?
- What technology have students at the college used in the classroom?
- What strategies are provided for students who use adaptive technology? Were they successful?
- What modifications have faculty and administrators been willing to make for students with disabilities on campus?
- Are there extra fees for special programs?
Role Play #2: You, as the adult, continue playing the role of the disability students services staff person, but now you get to ask the questions of the student. Use the following suggestions as a guide.

- Can you describe your educational background?
- Can you describe your disability?
- What are your strengths and weaknesses outside of the classroom?
- What adaptive equipment are you currently using?
- What training did you receive in using this adaptive equipment?
- Who provided your technical support?
- How did you communicate with your instructors about using your adaptive equipment in the classroom? How did they respond?
- What appropriate accommodations have you used to assist you for class, assignments, and exams?
- How have your accommodations helped you succeed?
Research shows that having a disclosure “script” and practicing it with friends, teachers, relatives, and mentors can be of great benefit to youth when the time actually comes to disclose. Most people find that it is easier to talk about the impact of having a disability rather than offering a formal or clinical definition.

For example, someone explaining that they have cerebral palsy could say:

“I have difficulty with fine motor skills. I write more slowly and with more difficulty than other people and become fatigued more easily. Consequently, I will need to use a computer to type essay tests or any other written assignments.”

It is also helpful to include some information relating to areas of strength. Here is one example:

“I am able to use my strong verbal skills to contribute and share my ideas during class while I tape record the entire lecture. If I took notes during the lecture instead of participating in discussion, I would find it difficult to keep up with the discussion.”

To help the young person practice explaining his or her disability, work together to develop and write his or her explanation. Take turns reading it aloud. Ask each other what worked and what didn’t. You may have to do this several times before the script truly describes what the young person wants to say in a way that someone who knows very little about disabilities will understand. Use additional paper if needed.

Here are some questions and hints you and the young person can think about while preparing the disclosure practice script:

- Write about his or her positive attributes or strengths first.
- Identify any limitations or challenges he or she faces in school because of his or her disability.
- Identify which accommodations have worked best for him or her in the past and why.
- Try to put yourself in the shoes of the person who will be listening to the young person’s disclosure and consider how to explain things to the faculty or staff member so that he or she knows how to help the young person.
- End the script with positive points such as how the young person expects he or she will succeed in the class or program with the necessary support.
Practice Script: ________________________________

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_________________________________________

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_________________________________________
Unit 8:

Disclosure on the Job...
Why, When, What, to Whom, and How?

PURPOSE

The purpose of Unit 8 is to increase understanding of and reiterate the need to disclose in order to receive reasonable accommodations in a work setting. In addition, this unit clearly answers the specific disclosure questions: why, when, what, to whom, and how to disclose in employment settings. We strongly suggest that you read the discussion on page 8-3.

YOUR ROLE

Your role as it relates to supporting a young person in understanding issues related to disclosure in a job setting is to help the young person build confidence. Consider this an opportunity to work with the young person on learning his or her rights and responsibilities in the workplace, which are very different than rights and responsibilities in the school environment.

TERMINOLOGY

You may know some of these words already, or you may have just heard them in passing. First, define these words, as you understand them. Then, check your definitions against the glossary that is located in the back of this workbook. The following terms are used in Unit 8:
<table>
<thead>
<tr>
<th>Essential functions of the job</th>
<th>Mentor</th>
<th>Social networking</th>
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<tbody>
<tr>
<td>Job accommodations</td>
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<td>Self-accommodate</td>
</tr>
<tr>
<td>One-Stop Career Center</td>
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<td>Qualified individual</td>
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</table>

Essential functions of the job: 

____________________________________________________________________________________

Job accommodations: 

____________________________________________________________________________________

Mentor: 

____________________________________________________________________________________

One-Stop Career Center: 

____________________________________________________________________________________

Self-accommodate: 

____________________________________________________________________________________

Social networking: 

____________________________________________________________________________________

Qualified individual: 

____________________________________________________________________________________

____________________________________________________________________________________
WHY to disclose on the job

Every job seeker with a disability is faced with the same decision: “Should I or shouldn’t I disclose information about my disability?” Ultimately, the decision of whether or not to disclose is entirely personal. It is a decision to be made only after a person with a disability weighs the personal advantages and disadvantages of disclosure (see Unit 4).

People with disabilities must consider the supports and services that they may need to be successful in the job of their choice. Remember that accommodations in the workplace are only provided when a worker discloses his or her disability and requests job accommodations. Employers and co-workers are not required to provide accommodations to workers who have chosen not to disclose their disabilities.

The process of learning how to disclose disability-related needs effectively and to develop an accommodation plan is extremely valuable. Effective disclosure skills require that a person 1) share information regarding his or her disability-related needs, and 2) provide creative, practical suggestions for job accommodations. It is important that youth with disabilities understand that open communication with their employers, work mentors, and co-workers can help them to evaluate the effectiveness of accommodations and make changes when efforts are not working.

Some job seekers choose not to disclose their disabilities because they believe that they can manage their careers in the same way as any other job seeker or because they have become skilled at developing compensatory strategies and have the ability to self-accommodate without assistance. Others decide not to disclose at work because they fear being treated differently or being denied the same opportunities as job seekers without disabilities.

On the other hand, many job seekers choose to disclose disability-specific information for a variety of important reasons and to a variety of different people (employer, work mentor, co-workers). The following list includes some (but definitely not all) of the reasons a person with a disability might choose to disclose:

- To obtain information to assist him or her in developing a career plan that addresses possible barriers and accommodations;
- To identify disability-specific employment services and support networks;
- To discuss employment requirements with recruiters or other professionals;
- To discuss disability issues with prospective employers to determine whether the requirements of the position can be met, with or without reasonable accommodation;
- To investigate the supports available at the workplace; and
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- To develop mentoring and peer support structures with employees and employers with disabilities.

Remember that it is not essential for a person with a disability to divulge specific personal information about his or her disability. Bringing a 2-inch thick medical history file to an employer is typically not the most effective route to go.

A disability is only important if it affects (or can potentially affect) a person’s ability to perform the essential functions of a job. As a first step, help the young person consider how his or her disability affects or may affect his or her ability to perform the essential functions of the job. Second, help him or her identify what supports would provide the most favorable environment for success in the workplace and possible accommodations to request in workplace situations. Remember, just as for any other person interviewing for a job, the prospective employer wants to know that the person being interviewed is qualified and can perform the core responsibilities including with accommodations and supports.

Informed decision-making is a critical skill, especially in the information age. There is an incredible amount of information that can be discovered about someone using “Google,” “Yahoo,” or other search engines. A lot of young people flock to social networking sites like MySpace, BlackPlanet, Facebook, and others to connect with their friends, post pictures, and find information. However, it is important to educate all youth about safety issues as they relate to these new ways of connecting. Inappropriate pictures are not the only things young people should be worried about others finding. Personal information, including information about one’s disability, is also available if put out into cyberspace.

“I was applying for a job I was qualified for and didn’t even get interviewed. I found out later that two people on the hiring committee “Google’d” me and found out that I belonged to a well-known disability organization and had given speeches on a number of different topics related to my condition. I now wonder if that’s why I didn’t get a call.”

It is therefore important that you remind the young person you are coaching of this “hidden” danger of sharing information in the public domain. In an age where employers routinely turn to the Internet to screen applicants, it is safe to assume that if it’s out there, it will be found.

WHEN to disclose on the job

Though there is certainly no one “right” time and place to practice disclosure being proactive is strongly encouraged. Being proactive means taking action before problems or challenges arise when possible. Being proactive puts workers with disabilities in better control of their lives.

When a person decides to disclose his or her disability to his or her employer, there may be settings and circumstances in which disclosure is more appropriate than others. Consider the following possibilities:

Remind the young person that employers can’t meet his or her needs if he or she doesn’t know what those needs are!
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<thead>
<tr>
<th>CIRCUMSTANCE</th>
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<tr>
<td>In a third-party phone call or reference</td>
<td>Employment counselors at the local One-Stop Career Centers have strong connections with local employers and may be willing to serve as a reference for a person with a disability. Help the young person with a disability think about how to make it clear with the counselor whether he or she would like the counselor to disclose his or her disability, and how he or she would like his or her disability to be represented.</td>
</tr>
<tr>
<td>In a letter of application or résumé</td>
<td>Many individuals choose to disclose their disabilities in their résumé or letter of application. Having a disability may be viewed as a positive trait in some professions or even as a requirement for some positions. For example, the Workforce Recruitment Program has been established specifically for young adults with disabilities.</td>
</tr>
<tr>
<td>In a cover letter</td>
<td>Some individuals disclose their disabilities in their cover letters. As a rule, the cover letter should be attached to the résumé so that the applicant’s skills can be the focal point. Again, having a disability is not always a strike against a potential employee. Some companies actively recruit people with disabilities to meet affirmative action goals.</td>
</tr>
<tr>
<td>Pre-interview</td>
<td>Disclosure prior to the interview is encouraged only when an accommodation is needed for the actual interview. For example, if a person uses a wheelchair and the office where the interview is to be scheduled is on the second floor of a building without an elevator, the potential employee would need to make the interviewer aware of his or her need for accommodations. For example, the youth may suggest that the interview be moved to a first floor location.</td>
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</table>
| On the employment application      | There may be several options if the employment application form asks something like, “Do you have any mental or physical limitations that may impact your performance on the job?”  

It might be the case that the young man or woman feels that his or her disability is not a limitation on his or her work performance and would therefore respond by answering, “No.” On the other hand, he or she might decide to use this as an opportunity to indicate that he or she has a disability that will not limit his or her performance if properly accommodated. Finally, the potential employee may just want to indicate that he or she would prefer to answer this question when he or she is called for an interview. |
## Unit 8: Disclosure on the Job

### The 411 on Disability Disclosure

#### At the interview
A person with a disability may or may not choose to disclose his or her disability during an interview. If the disability is visible, he or she may wish to discuss how it will not get in the way of doing a good job, especially if given the proper accommodations. At this time, a person with a disability could give examples of how he or she would perform the job. You can help the young person think this through. If the disability is not apparent invisible, he or she will need to decide whether or not to disclose his or her disability based on his or her own comfort and trust levels. The young person is not required to disclose his or her disability at this stage. However, it might be helpful to do so in order to show that he or she can do the job with the right accommodation. At this time, the young person might want to give examples. Advise him or her to be positive, upbeat, and confident in him or herself and to avoid sounding apologetic, defensive, or cocky.

#### After he or she has been offered a job
Many individuals choose to disclose their disabilities after they have been offered a job. They want to be selected for the position because of their skills, and worry that disclosure prior to the point may influence the interviewer's decision. However, once hired, they choose to disclose to obtain any accommodations needed to do the essential functions of the job. Also, if the job requires medical testing and he or she takes medications that will show up in a screening, an individual may choose to disclose this information to the employer at this time.

#### During the course of employment
Sometimes, individuals with disabilities do not recognize that their disabilities can negatively affect their job performance. This is especially true for youth getting their first full-time job. Sometimes, they may feel confident when they first begin a job, but become concerned later that they may have underestimated their need for an accommodation.

Remind the young person that it is his or her responsibility to ask for an accommodation if he or she needs one. It is always better to ask for it before his or her job performance is questioned. An employer cannot force an accommodation on a person with a disability, but has the final word in what accommodation he or she will receive after consulting with the person.

#### Never
If they are able to perform the essential functions of the job without reasonable accommodation, they need not disclose their disability.

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WHAT information to disclose on the job

Remember that preparation is essential when planning to disclose a disability to an employer. Think about the disclosure script you collaborated with the young person in developing in Unit 7. Is the information presented in a clear and concise way that is relevant to a job? If it is, terrific! If not, work with the young person to make some changes and practice rehearsing the disclosure conversation. Don’t forget to reinforce that it is unnecessary for them to disclose very detailed medical or personal information. Stress that it is best to get to the point, and keep it positive!

Here is some information that a young person with a disability might wish to present to an employer, supervisor, work mentor, or co-workers:

- General information about his or her disability;
- Why he or she has chosen to disclose his or her disability, including its impact on his or her job performance;
- The types of job accommodations that have worked for him or her in the past in previous jobs and in training situations;
- The types of job accommodations he or she anticipates needing in the workplace; and
- How his or her disability and other life experiences can positively affect his or her work performance.

Most importantly, remind the young person to keep the disclosure conversation focused on his or her abilities, not his or her disability.

To WHOM to disclose on the job

A job seeker with a disability might choose to disclose information when developing his or her career plan and searching for employment. He or she might disclose information to the following individuals:

- Career counselors
- Disability-specific adult employment services personnel
- One-Stop Career Center personnel
- Prospective employers or human resources personnel
- Workplace mentors

In selecting the person to disclose to, the youth should consider the following questions first:

- Does this person have the power to determine the reasonableness of the request for accommodation(s)?
- Can the person provide the required accommodation(s)?
- Is the person responsible for hiring, promoting, or firing?
- Is the person in a supervisory role, and will he or she support me?
- What experiences does this person have with similar disclosure situations?
- Do I have respect for this person and trust him or her to keep my disclosure confidential?

Remember that it is important to select a private, confidential, comfortable place to disclose and to allow enough time to discuss the impact of a disability. The person(s) to whom youth are disclosing might have questions, suggestions, or concerns that require more time for discussion.
We have talked a great deal about the rights afforded to the young person that you are working with as a person with a disability. It is important to understand that, as a person with a disability, the young person has significant responsibilities to him or herself and to his or her employers, supervisors, mentors, and co-workers. Some of these rights and responsibilities are outlined in the chart below:

<table>
<thead>
<tr>
<th>People with disabilities have the RIGHT to:</th>
<th>People with disabilities have the RESPONSIBILITY to:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Have information about their disability treated confidentially and respectfully.</td>
<td>• Disclose their need for accommodation if they desire any work-related adjustments.</td>
</tr>
<tr>
<td>• Seek information about hiring practices from any organization.</td>
<td>• Search for jobs that address their skills and abilities.</td>
</tr>
<tr>
<td>• Choose to disclose their disability at any time during the employment process.</td>
<td>• Inform the manager or interview panel about their need for appropriate interview accommodations in a timely manner.</td>
</tr>
<tr>
<td>• Receive appropriate accommodations in an interview so they may demonstrate their skills and abilities.</td>
<td>• Identify appropriate and reasonable accommodations for an interview.</td>
</tr>
<tr>
<td>• Be considered for a position based on their skills and merit.</td>
<td>• Negotiate reasonable accommodation(s) with an employer at the point of job offer and beyond.</td>
</tr>
<tr>
<td>• Be questioned in a respectful manner about their disability for the purpose of reasonable accommodation.</td>
<td>• Bring their skills and merit to the table.</td>
</tr>
<tr>
<td>• Be self-determined and proactive.</td>
<td>• Be truthful, self-determined, and proactive.</td>
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</table>
Course for Disclosure Examples

Read the following examples and determine a course of disclosure for each potential job seeker. First determine whether or not it is necessary for the job seeker to disclose his or her disability. Then think about the “why,” “when,” “what,” “to whom,” and “how” questions discussed earlier in this unit. Write your responses on the lines provided. If possible, discuss your answers with the young person and how he or she would answer each question. Encourage the young person to discuss the scenarios with peers who have disabilities or other trusted individuals and share ideas about different ways of handling disclosure.

1. Linda’s emotional disability has recently worsened and it has become difficult for her to perform some aspects of her job. Her psychiatrist has made some recommendations to her regarding changes in her work schedule.

Disclose? ____________________________________________________________

Why? ______________________________________________________________

When? ______________________________________________________________

What? ______________________________________________________________

To Whom? ____________________________________________________________

How? ______________________________________________________________

2. Jamal’s schizophrenia has been well controlled by medication for the past three years. He recently graduated from college with a 3.5 grade point average (GPA) and is ready to apply for a job in the graphic design field, but he’s a bit nervous.

Disclose? ____________________________________________________________

Why? ______________________________________________________________

A Workbook for Families, Educators, Youth Service Professionals, and Adult Allies who Care about Youth with Disabilities
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<tbody>
<tr>
<td>What?</td>
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<tr>
<td>To Whom?</td>
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<tr>
<td>How?</td>
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3. Carl uses a guide dog. He was recently called for an interview at a local IT firm.

<table>
<thead>
<tr>
<th>Disclose?</th>
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<tbody>
<tr>
<td>Why?</td>
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<tr>
<td>When?</td>
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<td>To Whom?</td>
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<td>How?</td>
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4. Andrea has been offered a part-time job as a bank teller. She has a hearing aid, is able to read lips, and speaks well.

<table>
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</table>
5. Josephina has arranged an interview with the supervisor of a large department store to discuss a position as a sales clerk. She wonders how much her learning disability in math will affect her ability to run the cash register and give correct change.

Disclose? ____________________________________________________________________________

Why? ________________________________________________________________________________

When? ________________________________________________________________________________

What? ________________________________________________________________________________

To Whom? ______________________________________________________________________________

How? ________________________________________________________________________________

6. Francisco has scheduled an interview at a small non-profit organization. He wonders if the building will be accessible for his wheelchair.

Disclose? ____________________________________________________________________________

Why? ________________________________________________________________________________

When? ________________________________________________________________________________

What? ________________________________________________________________________________

To Whom? ______________________________________________________________________________

How? ________________________________________________________________________________
Research shows that having a disclosure “script” and practicing it with friends, teachers, relatives, and mentors can be of great benefit to the youth when the time actually comes to disclose. Most people find that it is easier to talk about the impact of having a disability rather than offering a formal or clinical definition.

For example, someone who uses a wheelchair and is arranging for a job interview, might say:

“I’m really looking forward to this interview and I am checking to make sure that the interview room can accommodate my wheelchair.”

During an interview, a person with a hearing impairment who can lip-read and is concerned about communicating on the job might say:

“I can lip-read in face-to-face interaction, but will need TTY services and devices when using the phone.”

If an employer expresses concern about a worker’s productivity, the worker might say:

“I am having more difficulty than I anticipated keeping up with my co-workers because of my learning disability. In the past, it has helped to work alongside an experienced mentor.”

To help the young person practice explaining his or her disability, work together to develop and write the explanation. Take turns reading it aloud. Ask each other what worked and what didn’t. You may have to do this several times before the script truly describes what the young person wants to say in a way that someone who knows very little about disabilities will understand. Use additional paper if needed.

Here are some questions and hints you and the young person can think about while preparing the disclosure practice script:

Write about his or her positive attributes or strengths first.

Identify the limitations or challenges he or she may face at work because of his or her disability.

Identify which accommodations have worked best for him or her in the past and why.

Consider how disclosing can help the business employer and his or her co-workers (try to put yourself in the employer’s and coworkers’ shoes).

End the script with positive points such as how the young person expects he or she will succeed in the job with the necessary support.
Visit Your Local
One-Stop Career Center

You may not have heard of One-Stop Career Centers (One-Stops). One-Stops are centers designed to provide a full range of assistance to job seekers under one roof. They offer training, career counseling, job search opportunities, job placement services, and other employment-related services. If an individual goes to a One-Stop for some free training offered, he or she may work on interviewing skills, résumé writing, or learn about the resources available in the community, among other things.

To help the young person learn more about the One-Stop in your area and what services he or she can access there, complete the steps listed below with the young person:
1. Log on to http://www.servicelocator.org. Click on “Find a One-Stop Career Center” and enter your zip code. Record the location of the One-Stop Career Center closest to your home:

________________________________________

2. Make travel arrangements for you and the youth to visit the One-Stop Career Center to see which services are available. (This is also a great opportunity to acquaint youth with disabilities with public transportation services!) Check one:

_____ We can get there independently.
_____ We will ask ____________ for a ride.
_____ We will take public transportation.

3. Meet with the resource room counselor to discuss the services available to you at the Center.

We met with ______________________

His/her contact information (telephone/email) is: ______________________

_________________________________

4. Encourage the young person to ask for a tour of the resource room. With the youth, write down some observations about things that may help him or her conduct a job search. They were:

1. __________________________________
2. __________________________________
3. __________________________________

5. Find out about the classes and programs available to youth at the One-Stop. Depending on the age of the person with a disability, his or her actual disability, and his or her financial situation, different options may be available.

What are some general classes, which are available to everyone, that may be of benefit to the young person:

1. __________________________________
2. __________________________________
3. __________________________________

What additional services are offered to him or her because he or she is a person with a disability:

1. __________________________________
2. __________________________________
3. __________________________________

What services are available to him or her based on age:

1. __________________________________
2. __________________________________
3. __________________________________
Disclosure in Social and Community Settings...

Why, When, What, to Whom, and How?

**PURPOSE**

The purpose of Unit 9 is to explore the circumstances in which a young person may choose to disclose his or her disability to community members and friends in social situations. This unit clearly answers the following specific disclosure questions: why, when, what, to whom, and how to disclose in social settings. This is often the most difficult group of people for youth with disabilities to disclose to.

While teenagers often rebel and want to be independent from adults, peers can have a great influence during the teen years. Due to concerns about fitting in with peers, young people may want to avoid disclosing or setting themselves apart as “different” from their peers in any way.

Terminology provided in this unit will help you support youth to better answer these questions. We strongly suggest that you read the discussion section focusing on “why to disclose” on page 9-3.
Although disclosure is difficult in school and work settings, young people tell us the hardest situation to disclose in is a social one. Your role, as it relates to supporting a young person’s decisions about disclosure in social settings, is to help the young person think through whether and how to disclose his or her disability to others. Keep in mind that the times are different now than when you were growing up. The information age brings with it advantages and disadvantages for youth with disabilities with respect to socializing. For example, social forums on the Internet enable people to make many more social connections than in the past, but there are also more risks associated with putting “oneself out there” in cyberspace.

### TERMINOLOGY

The young person you are supporting might know some of these words already, however he or she may find it helpful to review and discuss the meaning of each term with you. Use the space below to reflect on the meaning of each term in your own words and then review the definitions provided in the glossary located in the back of this workbook. The following terms are used in Unit 9:

<table>
<thead>
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<th>Trust</th>
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<tbody>
<tr>
<td>Frustration</td>
<td>Role model</td>
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Community: ____________________________

__________________________________________________________________________

Frustration: ____________________________

__________________________________________________________________________

Role model: ____________________________

__________________________________________________________________________

Trust: ____________________________

__________________________________________________________________________
Social and community environments have barriers that sometimes prevent people with disabilities from spending time outside their home, socializing and going out with friends, and participating in community or civic events. According to some studies, less than three percent of youth with disabilities are actively involved in youth development and leadership activities including Boys and Girls Clubs, Scouts, 4-H, and other groups.

Speaking about a disability in social settings can be hard and sometimes frustrating because many of the barriers youth will face in social settings are people’s attitudes, beliefs, and inexperience. It is important to understand how a disability and disability-related needs can influence a person’s participation in community and other social activities such as recreation, leisure, civic, religious, and political activities. It’s also important to be supportive when youth have negative experiences with disclosure of a disability. Sometimes youth with disabilities feel that they aren’t afforded the right to be angry when they have their feelings hurt. This is part of their personal development and when adults respond with “sticks and stones,” or “be the bigger person” it only makes youth feel as though their feelings are that more invalid.

“Sometimes I have bad dwarf days. Days where I’m being chased down the street being called ‘Midget! Midget!’ by a bunch of kids. Then I go to the ATM to find that I can’t reach it. When I go on a date to the circus the ticket taker asks me if I’m part of the show. By that point I erupt. This is when it helps to have other friends with disabilities. They understand the frustration.”

It may be necessary for the young person you are supporting to disclose his or her disability to friends or community members and in social situations in order to participate fully in everything the community has to offer. It will be important for you to be supportive of him or her as he or she works out trying to explain his or her disability in several different ways, and to change the way he or she talks about him or herself in different situations. For example, talking about a disability to a soccer coach or Scout leader is very different from talking about a disability at a party or to someone the young person may want to date. The self-determination skills and informed decision-making skills discussed earlier in this workbook are important skills to have when deciding whether to disclose or not. This is also where it is helpful for youth with disabilities to have connections to the
disability community, engage with mentors with disabilities, and have friends or peer networks of youth with similar and different disabilities.

Again, this is where informed decision-making comes into play. Youth need to understand their own feelings, and balance them out with the information they have about the specific situation they are in at the time. The more questions he or she asks themselves ahead of time, the more he or she will know that the decisions they make are right for them.

Some examples of why youth with disabilities may choose to disclose in a social or community setting include but are not limited to the following:

Youth may wish to

• Start new relationships with honesty;
• Discuss specific needs in order to identify how to access needed accommodations in the community; or
• Receive any necessary assistance that may be needed while participating in community or social activities.

Remember that it is not essential for the young person to divulge specific personal information about his or her disability. What is most important and helpful is to provide information about how a disability affects his or her capacity to participate in social and community activities, and the supports that are needed to allow him or her to participate fully.

WHEN to disclose in social settings

There may be times when youth decide to disclose in social or community settings. The following list includes some possibilities:

• Going with their friends to a concert
• Planning a date with someone
• Meeting a mentor for lunch
• Meeting new people, or starting new relationships
• Joining community clubs or activities

WHAT information to disclose in social settings

Remember that what a young person discloses about him or herself is a deeply personal issue. He or she does not have to share everything with everyone. You should encourage the young person to think about what he or she wants people to know and to think about him or her. It will be helpful if he or she describes his or her disability and related needs in honest and positive terms.

The goal is to ensure people feel good about interacting with the young person, not pity him or her or view him or her as helpless.

Preparation is essential when planning to disclose a disability. Think about the scripts you worked together on in Unit 7 and Unit 8. Is the information presented in a clear and concise way that is relevant to the young person’s social and community life? If it is, terrific! If not, work with the youth to make some changes and have him or her practice the disclosure script.

Don’t forget that it is not necessary for him or her to disclose every detail of his or her medical or personal information even to friends. Help him or her determine what information is necessary to share and encourage him or her to be open, honest, and
comfortable in discussing his or her disability. Some people may feel uneasy talking about disability, which may cause hurt feelings or frustration, but a positive approach can help put others at ease. Too positive, however, and it may come off as inspirational. While that’s okay if that’s the impact that the youth wants, most youth want people to see them as a person as opposed to an icon. Preparation can help youth set the right tone.

The young person may wish to present the following information about his or her disability to friends, acquaintances, or community members:

- General information about his or her disability;
- Why he or she chose to disclose his or her disability to them, including its impact on his or her social life and community involvement;
- The type of accommodations that have worked for him or her in the past or that he or she may need in the future; and
- Positive examples of how he or she can become more involved in the community, and what community involvement means to him or her.

To WHOM to disclose in social settings

As a person with a disability, the young person may choose to disclose his or her disability to a variety of other community members. Oftentimes, disclosure may be made to the following individuals among others:

- Friends and acquaintances
- Relatives
- Owners or staff members of various businesses (e.g., grocery stores, banks, or clothing stores)
- Public transportation staff
- Parks and recreation staff
- Events coordinator
- Mentors or role models

There are certain questions that you can coach the young person to think about when deciding which person or persons to share this information with, such as the following:

- Do I have respect for this person and trust him or her to keep my disclosure confidential?
- Is disclosure essential to our relationship?
- Does this person have the power to determine whether a request for an accommodation is reasonable?
- Can the person provide the required accommodation(s)?
- Is this person going to use information about my disability to support me or harm me?

Remember that it’s important to select a private, confidential, comfortable place to disclose, and to allow enough time to discuss the impact of the disability. The person(s) youth are disclosing to might have questions, suggestions, or concerns that require additional discussion.
# Rights and Responsibilities

*Adapted from* [http://sites.uws.edu.au/rdlo/disclosure/education/prior.htm].

We’ve talked a great deal about the rights afforded to people with disabilities. Something very important to remember and reinforce with the young person is that, as a person with a disability, he or she also has significant responsibilities to him or herself and to others in his or her community.

<table>
<thead>
<tr>
<th>Persons with disabilities have the RIGHT to:</th>
<th>Persons with disabilities have the RESPONSIBILITY to:</th>
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</thead>
<tbody>
<tr>
<td>• Be treated fairly and in a non-discriminatory fashion.</td>
<td>• Investigate and fully understand their disability and disability-related needs as they pertain to community living and social activities.</td>
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<tr>
<td>• Have information about their disability treated confidentially and respectfully.</td>
<td>• Find out about options for accessing the community settings of their choice.</td>
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<tr>
<td>• Work collaboratively with others to identify necessary supports for their success.</td>
<td>• Advise community members and friends in a timely manner of their accommodation and support needs.</td>
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<tr>
<td>• Obtain information about disability support services as well as physical and programmatic access in community settings.</td>
<td>• Understand that community members and friends may not be able to address their needs effectively if they do not present them in a timely manner.</td>
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<tr>
<td>• Be self-determined and proactive.</td>
<td>• Be self-determined and proactive.</td>
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Course for Disclosure Examples

Read the following examples and determine each person’s course for disclosure. First, determine whether or not it is necessary for the person to disclose his or her disability. Then think about the “why,” “when,” “what,” “to whom,” and “how” questions. Write your answers on the lines provided. Remember that there are no “right” or “wrong” answers, because choosing to disclose is a personal, individual decision!

If possible, discuss your answers with the young person and how he or she would answer each question. Encourage the young person to discuss the scenarios with peers who have disabilities or other trusted individuals and share ideas about different ways of handling disclosure.

1. Yvonne wishes to join an after-school business club that meets at the public library two days per week. Most of the students walk to the library after school. The library is located within walking distance of the school. Yvonne has a mild form of cerebral palsy and can walk with the use of a cane. She is able to maneuver around the school, but is concerned about the walk on the sidewalk to the public library. She is very excited about joining the club but is concerned about the walking.

Disclose? 

Why? 

When? 

What? 

To Whom? 

How? 

2. Matthew and his friends from college have decided to attend a movie festival next weekend. Michael wears glasses, but his friends do not know that Michael has a severe visual impairment and must get preferred seating when he watches movies. In order to see the movies, he would need to sit very close to the screen.

Disclose? 

A Workbook for Families, Educators, Youth Service Professionals, and Adult Allies who Care about Youth with Disabilities
Unit 9: Disclosure in Social and Community Settings

<table>
<thead>
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<th>Why?</th>
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<td>To Whom?</td>
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<td>How?</td>
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3. Denise has difficulty reading. She receives accommodations for classes but has trouble when reading restaurant menus, buying movie tickets, or grocery shopping. She is getting ready for her first date, which will be tomorrow night. Denise is nervous about her date’s suggestion of dinner and a movie.

**Disclose?**  
**Why?**  
**When?**  
**What?**  
**To Whom?**  
**How?**

4. Brian has epilepsy and takes medication to control his seizures. Lately, he has been having seizures more frequently because his doctors are adjusting his medication. He has never disclosed that he has epilepsy to most of his friends at school, but is now worried that he might have a seizure at the senior prom, which is in three weeks. He has a date and still wants to go, but he is concerned that his friends will discover that he has epilepsy.

**Disclose?**  
**Why?**  
**When?**  
**What?**
5. José has registered to vote in the next presidential election. He has received notification of his election location. Because of his paralysis, he will need assistance in the voting booth. On Election Day, he cannot find someone he trusts to accompany him to vote.

Disclose? 

Why? 

When? 

What? 

To Whom? 

How? 

6. Keri has ADHD. She has just moved to a new city and is making new friends. Keri tends to overbook her social activities and consequently is often late meeting her friends or forgets to come at all. Her friends are becoming frustrated with her.

Disclose? 

Why? 

When? 

What? 

To Whom? 

How?
Research shows that having a disclosure “script” and practicing it with friends, teachers, relatives, and mentors can be of great benefit to youth when the time actually comes to disclose. Most people find that it is easier to talk about the impact of having a disability than offering a formal or clinical definition.

For example, someone with dietary restrictions as a result of diabetes is invited to celebrate a friend’s birthday with cake and ice cream. She might say:

“Because of my diabetes I can’t eat sugary foods, so if you don’t mind I’ll bring some sugar-free snacks for myself and to share with everyone else.”

In another example, a young man who uses a wheelchair has difficulty carrying objects in both hands. When he goes to a fast food restaurant with his friends, he might say to the cashier:

“Put my order in a bag.”

To help the young person practice explaining his or her disability, work together to develop and write his or her explanation. Take turns reading it aloud. Ask each other what worked and what didn’t. You may have to do this several times before the script truly describes what the young person wants to say in a way that someone who knows very little about disabilities will understand. Use additional paper if needed.

Here are some questions and hints you and the young person can think about while preparing the disclosure practice script:

- Discuss what his or her disability is all about including both strengths and limitations.
- Discuss how his or her disability affects his or her social or community life currently.
- Discuss what he or she would like your social or community life to include.
- Identify ways in which community members or friends can best accommodate the young person in social settings.
- Explain what his or her greater participation in the community can do for others.
Practice Script:

____________________________________________________________________

____________________________________________________________________

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____________________________________________________________________

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____________________________________________________________________
Unit 1

Charity Model — A previous model of disability in which people with disabilities were considered to be victims of tragedy and deserving of pity and protection from the demands of society. The term “handicap” came from the image of a person with a disability during the Industrial Revolution, who had a “cap in hand” to beg in the streets.

Cultural Minority Model — Established in the 1990s, this model of disability encourages people with disabilities to join together and form a separate cultural group similar to those that arise from ethnicity, race, or religion. The cultural minority model emphasizes the need to appreciate the differences that come out of being a person with a disability, as one would appreciate differences in ethnicity, race, or religion. Out of this model came the assertion that people should embrace the idea of a “disability culture” and be “Disabled and Proud!”

Disability — The Americans with Disabilities Act defines “disability” as: 1) a physical or mental impairment that substantially limits one or more major life activities; 2) a record of such an impairment; or 3) being regarded as having such an impairment.

Disability Culture — The shared experiences and sense of kinship among individuals with disabilities resulting from the oppression they face on political, social, economic, and cultural levels. The feeling of sharing a common experience is the initial sign of something more than just coincidences and experiences, but a deeper level of kinship.

Disability Pride — “A rejection of the notion that our physical, sensory, mental, and cognitive differences from the non-disabled standard are wrong or bad in any way, and is a statement of our self-acceptance, dignity and pride. It is a public expression of our belief that our disabilities are a natural part of human diversity, a celebration of our heritage and culture, and a validation of our experience. Disability Pride is an integral part of movement building, and a direct challenge to systemic ableism and stigmatizing definitions of disability. It is a militant act of self-definition, a purposive valuing of that which is socially devalued, and an attempt to untangle ourselves from the complex matrix of negative beliefs, attitudes, and feelings that...
grow from the dominant group’s assumption that there is something inherently wrong with our disabilities and identity” (Triano, 2005).

**Individualization** — A principle of national disability public policy that maintains decisions about someone with a disability are to be based on the individual’s strengths, resources, priorities, concerns, abilities, and capabilities, rather than on stereotypes, assumptions, and misperceptions.

**Equal Opportunity** — In the context of national disability public policy, equal opportunity means that programs and services must be accessible to, and usable by people with disabilities in the most integrated setting possible, considering the person’s unique needs and circumstances.

**Full Participation** — In the context of national disability public policy, full participation means all individuals with disabilities and their families have the opportunity “for active and meaningful involvement in decisions affecting them specifically as well as in the development of policies of general applicability, i.e., at the systems/institutional level. (‘Nothing about us without us.’) This means that policies, practices, and procedures must provide for real, informed choice; self-determination and empowerment; self-advocacy; and person-centered planning and budgeting” (Silverstein, 2002).

**Mainstreaming** — The practice of including students with disabilities in the same classrooms and other school settings as students without disabilities rather than placing them in special classroom settings isolated from those without disabilities.

**Medical Model** — A previous model of disability in which people with disabilities were considered to be broken and need to be fixed. For example, people who were unable to walk were often forced to wear heavy braces or undergo experiments and radical treatments to make them “whole” or “normal” again.

**Moral Model** — A previous model of disability in which people with disabilities were considered to be afflicted by the devil, or their disability was the result of a sin or punishment for wrongdoing by them or their family. In other words, the “external” disability represented a spiritual or internal “defect.”

**Social/Civil Rights Model** — A 1980-1990s model of disability which contended that systems, laws, policies, environments, and relationships continuing to keep people with disabilities isolated from society all need to change. This model promotes “inclusion,” “full participation,” “self-sufficiency,” and “independent living.”

**Unit 2**

**Accommodation** — Modifications or adjustments to the work environment or to the circumstances under which a particular task is customarily performed that enable a qualified individual with a disability to perform the essential functions of that position (including jobs, education, and community involvement).

**Empower** — To give individuals power and authority to control their own lives, to make decisions on their own, and to take actions on their own behalf (Marinelli & Dell Orto, 1999).

**Informed Choice** — The process by which an individual arrives at a decision. It is a process that is based upon access to, and full
understanding of, all necessary information from the individual’s perspective. The process should result in a free and informed decision by the individual about what he or she needs.

**Self-advocacy** — The process by which someone supports his or her ideals, beliefs or oneself.

**Self-determination** — The right and ability of all persons to direct their own lives, as well as the responsibility to accept the consequences of their own choices. Some of the skills that make someone self-determined or a successful self-advocate are the following:

- **knowledge of one’s strengths and limitations**
- **belief in one’s ability to achieve goals**
- **ability to start and complete tasks**
- **ability to assertively assert one’s wants, needs, and concerns**
- **ability to make decisions and see other options.**

**Self-efficacy** — Self-efficacy is a belief in one’s ability to obtain a goal (Martin & Marshall, 1995). Self-efficacy provides the foundation for human motivation, well-being, and personal accomplishment (Pajares, 2002).

**Self-esteem** — Self-esteem is the collection of beliefs or feelings that we have about ourselves, or our “self-perceptions.” How we define ourselves influences our motivations, attitudes, and behaviors and affects our emotional adjustment (Nemours Foundation, 2008).

**Self-sufficiency** — In the most extreme case, a self-sufficient person would be able to supply all of his or her own basic needs without the intervention of anyone else - from physical needs such as food and shelter to intangible needs such as happiness (Richards, 2003).

**Unit 3**

**Confidential** — Information that is private or secret to oneself.

**Disclosure** — The act of opening up, revealing or telling; intentionally releasing personal information about oneself for a specific purpose.

**Unit 4**

**Advantages** — Benefits resulting from a particular course of action.

**Disadvantages** — Unfavorable, inferior, or prejudicial conditions that result from a particular course of action.

**Impact** — To impinge upon or have consequences because of involvement or release.

**Self-image** — One’s conception of oneself or of one’s role; self-image may be positive or negative.

**Unit 5**

**Accessible** — Providing access to or capable of being reached or used; may also be used to describe architecture that can be reached or utilized by everyone, including those who use a wheelchair, a walker, or a cane.

**Adult Services** — Services needed for people when they reach adulthood; these services often include (but are not limited to) assistance in finding a job, assistance in the
home, assistance at work, and provision of various therapies or medications.

**Compensatory Strategies** — Actions one may take in order to offset difficulties a person may experience.

**Disability (under the ADA)** — A physical or mental impairment that substantially limits one or more major life activities, including (but not limited to) walking, eating, speaking, breathing, working, standing, or thinking.

**Discrimination** — Prejudiced or prejudicial outlook, action, or treatment against other persons, ideas, or ethics.

**Eligibility** — Criteria or requirements which determine a right to participate in a particular activity, service or program.

**Entitlement** — A right to benefits specified especially by law or contract; a government program providing benefits to members of a specified group; funds supporting or distributed by such a program.

**Free Appropriate Public Education (FAPE)** — The services to which every person ages three to 21 who is receiving special education services is entitled during their years in school.

**Hidden disabilities** — Disabilities that are invisible on the outside but that may limit an individual’s ability to function effectively.

**Individualized Education Program (IEP)** — A written statement for each child with a disability that is developed, reviewed, and revised in accordance with the Individuals with Disabilities Education Act (IDEA). This statement must include: A) the child’s academic achievement and functional performance; B) measurable annual goals, including academic and functional goals; C) a description of how the child’s progress toward the goals will be measured; D) what special education and related services will be provided; E) an explanation of the extent, if any, to which the child will not participate with nondisabled children in regular classes; and F) a description of any appropriate accommodations that are necessary. The first IEP, under the IDEA, must be in effect no later than when the child turns 16. These services may start earlier if determined appropriate by the IEP Team. IEP’s must also be updated annually (IDEA 2004).

**Individualized Transition Plan (ITP)** — A written plan that outlines what a student will need to live and work as an adult. This plan works as a bridge between the IEP and other transition plans.

**Visible Disabilities** — Disabilities that are more apparent to someone else because of exterior appearance.

**Summary of Performance** — The 2004 reauthorization of IDEA requires schools to issue a Summary of Performance (SOP) for students transitioning out of secondary school. The SOP, which is to be developed in lieu of an exit IEP, describes the youth’s academic, cognitive, and functional levels of performance. It also includes recommendations on how to assist the youth in meeting his or her postsecondary goals including the use of assistive technology and accommodations. Starting freshman year of high school, each of these areas is expanded upon to include the student’s present level of performance and the accommodations, modifications, and assistive technology that are essential in high school to assist the student in achieving progress.
Unit 6

**Barriers** — Something immaterial that impedes or separates; could be described as an obstacle.

**Modification** — An alteration in an object, environment, or activity that results in increased usability. The making of a limited change in something; the result of such a change.

**Reasonable Accommodation** — Those adjustments that may need to be made within a work or school setting to allow an otherwise qualified employee or student with a disability to perform the tasks required. Under the Americans with Disabilities Act, Reasonable Accommodation means: A) modification to the job application process; B) modification to the work environment or the manner under which the position held is performed; and C) modification that enables an employee with a disability to enjoy equal benefits and privileges of employment. The term “reasonable” implies that the accommodation is one that does not cause an undue hardship for the employer. Examples of workplace accommodations include making existing facilities used by employees readily accessible and usable by individuals with disabilities; restructuring jobs/establishing part-time or modified work schedules; reassigning to vacant positions; adjusting or modifying examinations, training materials, or policies; and providing qualified readers or interpreters. Under the Individuals with Disabilities Education Act (IDEA), the term “accommodation” is used primarily with regard to the development and provision of alternative assessments that are valid and reliable for assessing the performance of students with disabilities.

**Universal Design for Learning** — An approach that addresses and redresses the primary barrier to making expert learners of all students: inflexible, one-size-fits-all curricula that raise unintentional barriers to learning. Learners with disabilities are most vulnerable to such barriers, but many students without disabilities, such as Limited English Proficiency (LEP) individuals, also find that curricula are poorly designed to meet their learning needs (National Center on Universal Design for Learning, 2009). More information on Universal Design can be found at the National Center on Universal Design for Learning’s website, http://www.udlcenter.org/.

Unit 7

**Access** — Access implies the ability to find, manipulate, and use information, an object, a place, a service or a program in an efficient and comprehensive manner. Access can be programmatic or physical.

**Assistive Technology** — According to the Americans with Disabilities Act, assistive technology is “any item, piece of equipment, or system, whether acquired commercially, modified, or customized, that is commonly used to increase, maintain, or improve functional capabilities of individuals with disabilities.” Assistive technology helps people with disabilities to complete daily living tasks independently, assists them in communicating with other individuals, and provides access to education, employment, and recreation.

**Disability Support Services** — An office in a postsecondary institution that provides necessary information to students who need accommodations. In addition, these offices
provide training to faculty and staff on disability issues.

**Disclosure Script** — Something that is followed or read from that will outline the sensitive information you are revealing.

**Postsecondary** — Term used to describe settings that follow high school (such as trade school, college, or employment).

**Responsibility** — Moral, legal, or mental accountability; may also be reliability or trustworthiness.

**Rights** — The power or privilege to which one is justly entitled.

**Unit 8**

**Essential Functions of the Job** — Tasks that are fundamental and necessary to the performance of a given job.

**Job Accommodations** — Modification or adjustments specific to the work environment, or to the manner of circumstances under which the position held or desired is customarily performed, that enable a qualified individual with a disability to perform the essential functions of that job.

**Mentor** — Someone whom you trust, and who can serve as an advocate or guide.

**One-Stop Career Center** — Centers designed to provide a full range of assistance to job seekers under one roof. One- Stops were created under the Workforce Investment Act and offer training referrals, career counseling, job listings, and similar employment-related services.

**Qualified Individual** — ADA regulations define a qualified individual with a disability as a person with a disability who: “satisfies the requisite skill, experience, education and other job-related requirements of the employment position such individual holds or desires, and who, with or without reasonable accommodation, can perform the essential functions of such position” (EEOC, 1992).

**Self-accommodate** — To provide accommodations for oneself rather than requesting accommodations from employers, professors, or other persons in the community.

**Social Networking** — The act of connecting and interacting with individuals who share certain interests, perspectives, or experiences in common. Social networking on the Internet is a common activity among young people and becoming increasingly popular among adults. Various websites such as Facebook, MySpace, and BlackPlanet allow individuals to interact virtually with friends, family, and other acquaintances and share personal information such as journal entries, photographs, and videos.

**Unit 9**

**Community** — A group of people living together within a larger society; often described in terms of particular environments (such as stores, banks, parks, or churches).

**Frustration** — Sense of insecurity and dissatisfaction brought about by problems that are not fixed or needs that are not met.

**Role Model** — A person whose behavior in a particular position (for example, a student or an employee) is regarded highly or is imitated or looked up to by others.

**Trust** — Assured reliance on the character, ability, strength, or truth of someone or something.
References


