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## Youth and Disability Disclosure: The Role of Families and Advocates

*This InfoBrief highlights NCWD-Youth's **The 411 on Disability Disclosure**, and explores the role families and advocates play in helping youth understand the importance of appropriate disability disclosure.*

Youth with disabilities face many challenges as they move from secondary education to competitive employment, postsecondary education and training, and community participation. Families play a vital role in supporting youth during this transition, often functioning as a youth's first, most knowledgeable and most consistent "case manager," who not only assists with service coordination and career exploration, but also provides transportation, housing, and other supports.

One vital aspect of a successful transition for youth with disabilities that is often overlooked is appropriate disability disclosure. When youth are in the secondary school system, they are participating in a system of *entitlement*, where educational services for youth with disabilities are required by Federal law. Once a youth moves to adult systems, whether they are disability-focused or not, there are *eligibility criteria* that have to be met to receive services. Many youth and families are confused when they move from a world where supports were assumed to be available to a world with new and unfamiliar adult eligibility requirements. Adding to the confusion, adult services are often provided through multiple agencies with eligibility requirements that differ from agency to agency. Often, disclosure is the key to accessing adult services and the kinds of disability-related accommodations the youth received in special education from postsecondary settings and in employment. Therefore, families and advocates need to help youth understand the importance of disclosure and work to prepare youth to disclose appropriately.

### **The 411 on Disability Disclosure: A Workbook for Youth with Disabilities**

The National Collaborative on Workforce and Disability for Youth (NCWD-Y) has developed a workbook to help youth understand the importance of disclosure and to guide them through various situations where disability disclosure may be an issue. This guide, *The 411 on Disability Disclosure: A Workbook for Youth with Disabilities*, is for youth who want to:

- understand themselves better;
- understand their disability better;
- explain their disability better to others;
- have help deciding whether or not to disclose their disability;
- feel better prepared to meet the challenge of disclosing their disability;
- better understand how disclosing their disability could improve educational, employment, and social opportunities.



The workbook aims to help youth answer five basic questions about disability disclosure:

1. Should I disclose?
2. If I decide to disclose, who is an appropriate person to tell?
3. When should I disclose?
4. How much should I disclose?
5. What should I disclose?

## **The Role of Families and Advocates in Disclosure**

Many youth with disabilities face barriers to competitive employment, postsecondary education, and independence. Some of these barriers may arise from their not having been timely identified as having a disability or their not fully understanding the impact of their disability. In addition they may not have considered how their disability impacts their need for accommodations outside of the special education setting. For example, a youth with a diagnosed anxiety disorder may be struggling to keep a job in a retail environment, and she, or her family, may not understand why failure keeps happening. Knowing the way a disability manifests itself in an unpredictable retail environment and disclosing the disability to access job accommodations may be key to the youth achieving success rather than struggling.

Although families can help youth develop a better understanding of their disability; they are often unaware of how critical it is for youth to develop this self-knowledge. Many families also assume that youth are taught about their disability in school, when, in fact, this is rarely the case. Disability is also a topic some families and educators feel uncomfortable discussing directly with youth, preferring to focus on the student's strengths and abilities. As a result, many youth with disabilities reach adulthood without a good understanding of the impact of their disability and the accommodations they can utilize to be successful. Many youth also resist the notion that they have a disability, fearing that being labeled as a person with a disability makes them different from their peers. As a result of these factors, and others, youth frequently enter the adult world unprepared to advocate for themselves. *The 411 on Disability Disclosure* is a tool that can be used by families to help guide youth through the self-awareness and disclosure process.

### *Why is Disclosure Important?*

“Disclosure” by definition means to make something known. This implies that disclosure of any kind is a personal decision; as such the decision as to whether and what to disclose about one's disability in an employment or postsecondary situation is something that should be up to the youth to determine.

Youth and families need to be reminded however that disclosure of a disability is required to secure “reasonable accommodations” in the workplace and academic accommodations in postsecondary settings. In addition, it is often necessary to become eligible for public supports such as Supplemental Security Income (SSI benefits) and Vocational Rehabilitation services.

In some instances where a person's disability is apparent, disclosure of the disability may be less of an issue than understanding how the disability impacts work, learning, and social interactions. A youth with a visible disability therefore may need the family's help in practicing how to discuss these types of issues and to learn how to effectively advocate for accommodations.

### *Weighing the Advantages and Disadvantages*



There are both advantages and disadvantages to disability disclosure. Families and advocates can help prepare youth for the potential consequences of disclosure by assisting youth in recognizing and thinking through the advantages and disadvantages of disclosure in a particular setting. For example, disclosure may be warranted when applying for support services available to people with disabilities in the community, because it is less likely to result in discrimination than in other venues, and is more likely to improve one's chances to be found eligible for a the program.

Disclosure in employment settings, however, can be another matter. Although disclosing a disability is essential for securing accommodations and civil rights protections, many believe that it also opens applicants up to being bypassed based on disability.

There is no easy answer to the question "should I disclose?" The list of advantages and disadvantages provided below can serve as a guide to youth and families when making the decision to disclose a disability or not.

### Advantages of Disclosure

- It can facilitate access to reasonable accommodations which may be needed for the youth to function most effectively in work, school, or community settings.
- It provides legal protection against discrimination (as specified in the Americans with Disabilities Act (ADA) and other disability nondiscrimination laws).
- It may reduce stress, since protecting a "secret" can take a lot of energy.
- It ensures that the young person is getting what s/he needs in order to be successful (for example through an accommodation or medication).
- It provides greater freedom to communicate should you face changes in your particular situation.
- It may help to improve the youth's self-image through self-advocacy and self-confidence.

### Disadvantages of Disclosure

- It can lead to the youth experiencing exclusion.
- It can cause the youth to become an object of curiosity.
- It can lead to the youth being treated differently than others.
- It can lead to the youth being viewed as needy, not self-sufficient, or unable to perform on par with peers.
- It can bring up conflicting feelings about the youth's self-image.
- Disclosing personal and sensitive information can be extremely difficult and embarrassing.

### Rights and Responsibilities: A Note

As mentioned earlier, youth with disabilities moving from school to community participation also move from a system where they are entitled to services to one where services and supports are only available to those who establish eligibility. One by-product of this shift is the differing definitions of disability held by youth and various adult systems. Families and advocates need to be aware that in the world of adult services and protections for people with disabilities, the burden is placed on the individual to disclose, and if necessary, provide documentation of the disability. Families should help youth maintain all relevant records pertaining to disability evaluations and assessments in case they are needed.



The ADA is the main civil rights law that provides protections against discrimination for people with disabilities in private sector employment; activities of states and local governments; places of public accommodation; transportation; and telecommunication services. It should also be noted that many states have human rights laws that provide additional protections. Families can help youth understand the extent of these protections, and access the resources that can help if discrimination is suspected. These resources include your state's Client Assistance Project and your local office of the U.S. Equal Employment Opportunity Commission (See Selected Resources below).

### *Disclosure on the Job*

There is no law that says a person with a disability has to disclose that disability to a current or prospective employer. Conventional wisdom states that disclosure should only take place if some type of reasonable accommodation is needed for a person to perform the essential functions of a job. For example, if the young person has a disability that limits their ability to lift heavy objects, but the job description does not require heavy lifting, disclosure may not be called for.

Unfortunately, many youth experience struggles in the workplace and don't realize that their disability could be a root cause. For example, a person with a severe learning disability might be having trouble taking multiple step directions, which can lead to negative work evaluations. If that person understood the impact of their disability, they could disclose, and ask for a reasonable accommodation such as a device that records work directions. Having appropriate job accommodations can be key to having a successful work experience.

If a person makes the decision to disclose a disability during the job application process there are many times which it can be done. Some youth may disclose to a job counselor or case worker from an employment program. This allows the counselor to help identify accommodations and practice interview techniques and responses with the youth. Within the application process a person, who chooses to do so, can disclose at any time between submitting a cover letter to the time when a position is offered. Regardless of the timing of the disclosure, the youth needs to be trained to highlight the abilities s/he brings to the job, not just their disability.

Employers are often very willing to hire people with disabilities, and respect candidates who come prepared to discuss the accommodations they need. Families and advocates can assist youth by helping them learn about the skills needed for a given job, identifying what accommodations might be needed, and practicing discussion points on strengths that can be used during an interview. This preparation can boost a youth's self-image and confidence when seeking employment

### *Disclosure in Post-Secondary Settings*

Youth and families sometimes hold the mistaken belief that post-secondary institutions are required to provide academic accommodations and modifications the same way they were provided while the youth was in high school. The truth is that, unlike in high school, the process of securing academic accommodations in post-secondary education settings is contingent upon the student asking for them. This is most often done through a separate office at the college, sometimes called Disability Student Services. Youth with disabilities are entitled to academic accommodations, such as note takers or extra test taking time, but should not expect the curriculum to be modified in any way. In post-secondary



education, accommodations are designed to ensure equal access to academic learning, but the core expectations of what needs to be learned do not change.

Families need to understand that post-secondary institutions will vary in the ways they grant and provide academic accommodations. It is essential that a youth have discussions about potential accommodations with a school before enrolling. There may be times that a school is not willing to provide the accommodations necessary for a student. Youth should be well-versed on the impact of their disability on their learning style and be able to advocate for the accommodations they need. It may be necessary for a youth to speak with several schools before finding the right fit. Failure to have these initial conversations can lead to misunderstandings and create barriers to post-secondary success.

### *Social and Community Settings*

The discussion about disability disclosure is not limited to employment and academic situations. Youth and families should also recognize that social and community settings may require disclosure as well. Traditionally, many people with disabilities experience increased feelings of social isolation. This may be a result of the impact of the disability or an unwillingness to disclose a disability for fear of negative responses. Youth with disabilities should understand that their disability alone does not define them as a person, but rather is only a small part of who they are as individuals.

The same work families do with youth to prepare them for disclosure in work and school can be transferred to social settings. Families can encourage youth to openly discuss their disability, and to identify situations in the community where disclosure may be necessary. Examples of this may be when starting new relationships, when participating in community or social activities, or when identifying accommodations needed in the community, such as accessible transportation.

### **Summary**

Disability disclosure is an important aspect of securing accommodations in work and academic settings. It also plays a role in meaningful social and community participation. Disclosure is always a personal choice, and comes with advantages and disadvantages. Families of youth with disabilities need to recognize the value of preparing youth to disclose appropriately. By helping the youth to develop a better understanding of their disability and to develop self-advocacy skills, the youth will not only gain an improved self-image, but in addition will be able to effectively access disability related accommodations they may need for success in the adult world.

### **Selected Resources**

#### ***The 411 on Disability Disclosure: A Workbook for Youth with Disabilities***

This publication is designed for youth and adults working with them to learn about disability disclosure. This workbook helps young people make informed decisions about whether or not to disclose their disability and understand how that decision may impact their education, employment, and social outcomes.

<http://www.ncwd-youth.info/resources & Publications/411.html>

***Equal Employment Opportunity Commission (EEOC) Field Offices***



The EEOC enforces federal legislation prohibiting discrimination in employment to ensure equality of opportunity.

<http://www.eeoc.gov/offices.html>

***American with Disabilities Act (ADA) homepage (employment only)***

Website provides information and technical assistance on the Americans with Disabilities Act.

<http://www.usdoj.gov/crt/ada/adahom1.htm>

***Job Accommodation Network (JAN)***

JAN is a free consulting service designed to increase the employability of people with disabilities by: 1) providing individualized worksite accommodations solutions, 2) providing technical assistance regarding the ADA and other disability related legislation, and 3) educating callers about self-employment options.

<http://www.jan.wvu.edu/>

***Association on Higher Education and Disability (AHEAD)***

AHEAD is the premiere professional association committed to full participation of persons with disabilities in postsecondary education.

<http://www.ahead.org/>

***National Collaborative on Workforce and Disability for Youth (NCWD-Youth)***

The National Collaborative on Workforce and Disability for Youth assists state and local workforce development systems to better serve youth with disabilities.

<http://www.ncwd-youth.info/>

***PACER Center***

Minnesota based Parent Training and Information Center that works nationally to improve opportunities for youth with disabilities and their families, and provides training and technical assistance to a network of Parent Centers across the country.

<http://www.pacer.org>

***Parent Training and Information Centers by state***

Complete listing of Parent Training and Information Centers and Community Parent Resource Centers by state.

<http://www.taalliance.org>

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 in Washington, DC. The Collaborative is charged with assisting state and local workforce development systems to integrate youth with disabilities into their service strategies. This Information Brief was written by Marianne Mooney and Richard Luecking of TransCen, Inc. To obtain this publication in an alternate format please contact the Collaborative at 877-871-0744 toll free or email [contact@ncwd-youth.info](mailto:contact@ncwd-youth.info). This Information Brief is part of a series of publications and newsletters prepared by the NCWD/Youth. All publications will be posted on the NCWD/Youth website at [www.ncwdyouth.info](http://www.ncwdyouth.info). Please visit our site to sign up to be notified of future publications. This document was developed by the National Collaborative on Workforce and Disability for Youth, funded by a grant/contract/cooperative agreement from the U.S. Department of Labor, Office of Disability Employment (Number #E-9-4-1-0070). The opinions expressed herein do not necessarily reflect the position or policy of the U.S. Department of Labor. Nor does mention of trade names, commercial products, or organizations imply the endorsement by the U.S. Department of Labor. Individuals



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