

GW HEATH Resource Center

The Disclosure Dilemma For Advocates

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Should you? Shouldn't you? When? To whom? Such questions frequently arise for parents, counselors, and teachers whenever the topic of disclosure of a disability arises. Many disabilities, such as certain learning, cognitive, and perceptual disabilities, are not readily apparent. Students and employees with hidden disabilities may be understandably reluctant to disclose information about the presence and nature of a disability for fear of discrimination and negative perceptions.

Many factors can influence the ultimate decision of whether or not disclosure is the best course of action in a given circumstance. Young adults engaged in the transition to postsecondary education and employment will benefit from counsel and guidance about how to make sound judgments regarding disclosure.

Counselors, advocates, and family members should reinforce any advice regarding disclosure with instruction about effective self-determination and self-advocacy, concepts with which students in transition should be familiar. Ultimately, students and employees with disabilities who can articulate their particular needs and objectives, and who have been coached on the selective sharing of personal information, enjoy greater control over their circumstances.

Questions About Disclosure

There are many points of view about whether or not it is necessary or beneficial to disclose information about a disability, and, as noted above, many valid concerns about when, how and to whom such information should be shared. The following questions will guide students and advocates to a clear understanding about this difficult issue.

Why to Disclose?

There may be any number of reasons that an individual is confronted with a decision about disclosure:

- An accommodation is needed
- Legal reasons
- Background check is pending
- Safety or other health related reasons

When the disclosure question arises, individuals with disabilities need to address their own feelings about sharing personal information related to the disability.

When to Disclose?

The choice of when to disclose depends on the type of information being shared. Generally, disclosure occurs:

- When the individual is assured of the confidentiality of the information being shared, and never before.
- During initial contact, such as a job application.
- When an interview is scheduled.
- During an interview.
- Following a job interview or acceptance into a program.
- Any time after employment or program has started.
- Never.

Students and employees may choose never to disclose if no accommodations are needed and their disabilities create no safety issues for themselves or classmates and co-workers.

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What to Disclose?

Once the decision to disclose is made, one must still consider how much is too little, too much, or just enough personal information to share in light of the desired objective. Always be focused on the *purpose* of disclosing. When providing information about a disability, it is best to:

- Be honest, straight forward, factual, and positive.
- Relate disclosure comments to the immediate situation.
- Know your accommodations needs, and be prepared to offer suggestions regarding such things as costs, suppliers of needed devices, and knowledge of maintaining a piece of assistive equipment.
- Be prepared to provide appropriate documentation of the disability.

Who to Tell?

Not every person that students or employees with disabilities encounter throughout the day needs to know about the disability. Generally, those who might need to know about the disability are:

- Anyone directly involved in providing accommodations.
- Anyone who is positioned to support the request for accommodations.
- Anyone who is responsible for evaluating the student or employee's performance.
- Anyone responsible for the health and safety of other students or employees.

How to Disclose?

How, or in what form, information about a disability is best shared depends, in part, on when the individual chooses to disclose, and how much information they intend to share. Generally, the disclosure may be:

- Verbal: e.g., a perspective job applicant requests an accommodation in order to complete the application and interview process.

- Written: e.g., in response to an acceptance letter, a student notifies a college about the disability and need for accommodations.
- Third party: e.g., an advocate, such as a job coach, requests assistance on behalf of an employee with a disability.

Where to Disclose?

Students, employees, and advocates should take great care in choosing a setting in which to disclose. Without question, any information of a personal nature should be provided:

- In a private setting.
- In a place where only the intended recipient of the information will be informed.

Instructive advocacy leads to effective self-advocacy. Openly discuss prospective students' and employees' questions and concerns about disclosure. Actively engaging their input in the process will prepare them to handle similar future challenges independently. Taking the time to sort through these questions will also convey a sense of empowerment, and an understanding that, like any other students or employees, they too are entitled to privacy and dignity.

Disclosure Do's and Don'ts for Advocates

The following is a list of Disclosure Do's and Don'ts for Advocates:

DO:

- Link discussion of disclosure to self-determination and self-advocacy.
- Engage the youth/young adult in a discussion regarding thoughts and feelings on disclosing personal information.
- Determine the reason for needing to disclose.
- Weigh benefits and risks of disclosure or not disclosing.

- Plan and, if necessary, practice with the youth how to disclose personal information.
- Determine who needs to have this personal information and why; limit information sharing to essential persons.
- Assure the youth that both written and verbal information will be maintained in a confidential manner.
- Get the permission of the youth and parents/guardians to share personal information.
- Relate disclosure comments to current situation.
- Be aware of accommodation needs; be prepared to provide appropriate documentation.
- Discuss private information in a private setting.

DON'T:

- Share personal information about the youth/young adult without his/her consent and involvement, or the consent of parents/guardians.
- Discuss personal information regarding the youth/young adults with persons who are not involved in their service delivery.
- Ask personal or specific questions in a group or public settings.
- Leave written information in an area that may be read by others not involved in the delivery of services to the youth.
- Use confidential information for any reason(s) other than the purpose for which it was collected, disclosed and indicated to youth and parents/guardians.

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