

Self-Advocacy and Self-Determination in Transition

For Students and Families

What is Self-Advocacy and Self-Determination?

Self-advocacy is the ability to effectively communicate, negotiate, or assert your own interests, desires, needs, and rights. It involves making informed decisions and taking responsibility for those decisions (VanReusen et al., 1994). This is not a new concept, as it has been part of federal legislation for people with disabilities for some time. Dr. Bengt Nirje first described self-advocacy in Sweden in the 1960s. Self-determination is a right that all people have. It means making one's own choices and setting one's own goals. In the 1970s, Robert Perske called for action to support self-determination and the opportunity for people with disabilities to control their own lives. This laid the foundation for a special education initiative and a focus on the "dignity of risk" that continues today.

Leaving high school and moving into adult life is a momentous change for anyone. It is particularly challenging for students with disabilities who may or may not have had the chance to develop their voice and understand how to use it. The school years are essential to developing self-advocacy and self-determination skills and having opportunities to practice those skills. For students with disabilities, decision making is complicated by the perceptions of others about the choices available and the tendency for others to tell students what to do. Too often, adults inadvertently promote student dependence, passivity, and reliance on others by not teaching or expecting self-advocacy and self-determination skills.

In the monograph titled "Transition and Self-Advocacy" (West, Corbey, Boyer-Stephens, & Jones, 1999), the authors state:

Good self-advocates know how to ask questions and get help from other people. They do not let other people do everything for them or tell them what to do. Self-advocates are assertive. Assertive people tell others what they want and need, but they do not demand. They respect the rights and feelings of other people. They talk over their ideas with other people. They ask questions for guidance, then make up their own minds after reviewing the information. They may have strong feelings, but they try to be objective when making their decisions.

The Role of Families in Fostering Self-Advocacy and Self-Determination

Families play a key role in promoting self-advocacy and self-determination. They are the constant in a sea of change. While families may experience many challenges and obstacles, they also know how to improvise, adapt, and overcome. Teachers, service providers, and other team members support families in this role by understanding their concerns while showing them new ways to address them. Even when some ideas feel unfamiliar, families and students should be able to explore options, knowing they have the tools to navigate any changes successfully.

Developing Self-Advocacy and Self-Determination Skills

Since students have the biggest stake in the outcome of transition planning, they should have the biggest role. As an active team member, students can learn to exercise their rights and begin to see the results in their work life, education, community living, and more. Educators must encourage students to express concerns, preferences, and conclusions about options. That way, students gain the confidence to state their goals and interests so that others listen and respect their views. Since the goal of transition planning is maximum independence, the entire transition team must recognize self-advocacy as a critical component.

Developing the skills to advocate for oneself and sharing interests, skills, and support needs is complex and takes time and experience. It involves continuous learning and understanding that as one progresses, needs will change. When a person knows what helps them learn, what supports can make them successful at work, and where those supports are available in the community, they are better equipped to ensure those supports are in place when needed and advocate with adult service providers.

Start Early

Students should start developing self-awareness and decision-making skills early in their school careers. Students should also participate in their IEP meetings during elementary or middle school. By age 14, they should be actively involved in transition planning and even leading their IEP meetings. In high school, students should be involved in compiling relevant information to share with others, including:

- documents that identify their disability and support needs,
- a list of strengths,
- home or work accommodations needed,
- a summary of learning preferences,
- letters of recommendation, and
- telephone numbers of service providers.

Teach and Model Self-Advocacy and Self-Determination at Home

Family members are critical to the development of these skills. Young people are always watching- give them opportunities to practice and model skills at home. Below are some examples of how parents can encourage self-advocacy in their children:

- 1. Give students the language to ask.**

Young people may not know what to say when they want or need something.

- 2. Let students do things on their own.**

This can help build self-advocacy, even if they seem to struggle.

- 3. Role-play tricky situations.**

Responding to situations like asking for help at work or advocating for accommodations with a provider becomes much easier when students have thought through their responses.

- 4. Introduce students to role models.**

Reading about or visiting with others who stick up for themselves and others can be empowering.

- 5. Help the student to keep records.**

Students should gather information on their own for planning meetings and be part of presentations, so they understand its importance.

- 6. Involve the student in decision-making.**

As soon as possible, give the student options and empower them to make decisions.

Support Everyone's Voice

What about students with more severe disabilities and those with more limited communication? Family and friends can also help to ensure the voice of those with limited communication is heard by summarizing and sharing strengths, interests, and support needs. For example, one family member created a video featuring her daughter's friends. She asked them, "What do you like about having Iris in class?" "What is Iris good at?" and "What do you think Iris wants to do when she grows up?" You can also help the student develop PowerPoint presentations where they express their dreams, bring in items the student has produced, and show videos of other family members sharing what they feel is important to the person.

Work with Professionals

How should teachers and other professionals support self-advocacy and self-determination? They must work on building these skills throughout a student's school classes and experiences. Professionals must encourage students to be their own advocates by listening and asking for

input on accommodations or modifications needed. This includes helping students consider the pros and cons of solutions/concerns.

Below are some strategies families and students should insist that professionals adopt:

- Role-playing situations and helping students evaluate their responses. For example:
 - Asking for accommodations needed for a course.
 - Meeting with a rehabilitation counselor or social service caseworker.
 - Setting up a medical appointment.
 - Interviewing for a job.
 - Making choices in a transition planning meeting.
- Providing opportunities to practice skills, such as:
 - Involvement in student government.
 - Classroom decision-making exercises.
 - Evaluating past decisions or those made by others through case studies.
- Teaching each part of the decision-making process, such as:
 - Clearly defining the decision.
 - Weighing pros and cons.
 - Learning from each choice.

Take Responsibility

Developing self-advocacy and self-determination skills requires students to take increasingly more responsibility for decisions affecting their lives. This includes directing their Transition IEP. That leadership role necessitates completing some essential tasks, including:

- When considering a student's future, it can be challenging to envision adulthood. However, understanding that their decisions today will have implications later on is important. By focusing on what matters most to them, the team will be better equipped to guide their planning effectively.
- Ask parents and teachers for input on the student's goals. Their family and teachers know them best and can offer ideas that align with a student's skills and interests.
- Sharing the student's feelings with the transition planning team. Students can take an active role on the team by communicating from the start about what they want from the team. It is their life.
- Following up on objectives set up in the transition plan. When the student and the IEP team decide on a set of activities and objectives in the plan, the entire team

should ensure those experiences occur. If something is not working, students should communicate that to the team.

- Consider supported decision making. Having decision-making support is a step toward independence and fosters learning throughout the process. This approach enables students to start with small choices when they are young, gradually building up to larger and more complex decisions.

Enroll in Pre-Employment Transition Services (Pre-ETS)

Indiana Vocational Rehabilitation (VR) works with local service providers across the state to help schools prepare students for adult life through a program known as Pre-ETS. Eligible students are those with a disability in a secondary, postsecondary, or other recognized education program who are between the ages of 14 and 22 years old. These students are eligible for, and receiving, special education or related services, or are considered to have a disability for purposes of Section 504. Review the Indiana VR video on [Pre-ETS](#) for more information.

One of the five core instructional requirements of Pre-ETS is self-advocacy instruction. Students can enroll in this program through the transition planning process. Providers will work on self-advocacy using real-world employment experiences during the school day. Providers work with school systems on identifying students and determining the appropriate Pre-ETS curricula that will supplement, but not replace, existing school activities and meet each student's needs.

Conclusion

Developing self-advocacy and self-determination skills is as much about the adults in students' lives as it is about students themselves. Adults are responsible for actively teaching, practicing, and promoting these skills from an early age. Students rely on adults in their lives to respect their wishes and choices, even when they differ from those of adults. Quality of life depends on feeling in control of one's life, which is the goal of being self-determined and a strong self-advocate.

Resources

- ✓ IN*SOURCE: [Student-Led Transition Planning](#)
- ✓ Project 10: [Transition Education Network, addressing law and policy, effective practices, and research-based interventions in transition services for youth with disabilities.](#)
- ✓ National Center on Transition and Employment: [Advice & Guidance](#)
- ✓ PACER Center Videos: [Self-Advocacy: Find the Captain in You!](#)
- ✓ Pacer Center: [Preparing for Adulthood](#)

- ✓ LD On-Line: [Transition and Self-Advocacy](#)
- ✓ Zarrow Institute on Transition & Self-Determination: [ChoiceMaker Self-Determination Transition Curriculum](#)

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