

# Chapter 3: The Center of the Community: The Student and Family

*“Each person designs his own life, freedom gives him the power to carry out his own designs, and power gives the freedom to interfere with the designs of others.”*

—Eric Berne  
1910-1970, Psychiatrist, Writer

## Introduction

Students and families are the primary stakeholders in the transition process, and bear the majority of responsibility as well as reward for effective transition. As students first enter the transition process they usually play a less active role than their parents. However, as they get older they ultimately become solely responsible for their transition from dependence to independence. The VR counselor may be the first person in the student’s life that is obligated, by law, to deal with the student as an autonomous (or soon to be autonomous) adult. Up to this point, everyone providing services—primarily the school system and the medical profession—have an obligation to work with the parents/guardians.

## The Most Important Player: The Student

Like all students, youth with disabilities have dreams and ambitions and can be productive members of society. While transition is a normal process experienced by all students and their families, students with disabilities, because of their unique circumstances, benefit from beginning the transition process much earlier than other students. Practice has shown that students who participate in transition planning earlier by doing simple things like refining interests and talents attain more goals and have an easier time attaining them (Anderson-Inman, Knox-Quin, & Szymanski, 1999).

The student’s dreams, interests, and goals must drive transition planning. Students must be given every opportunity to understand their options and lead the process. These are skills that youth must develop, with appropriate supports and opportunities. Depending upon their disability, levels of self-advocacy and self-determination differ, nevertheless ALL students need to know what self-advocacy and self-determination are.

Assuming responsibility for informed choice over what is essentially the beginning of the rest of the student’s life requires:

- Developing an understanding of self, including strengths and needs,
- Being able to communicate desires, ideas, and values,
- Understanding short and long term affects of disability,
- Wearing or using all necessary assistive devices, despite teenage desires to fit in,
- Being able to disclose his or her disability, when appropriate,

- Knowing and requesting preferred accommodations,
- Understanding disability culture,
- Learning and practicing self-determination skills,
- Preparing to take on adult roles and responsibilities.

## Importance of the Family

Families of youth with disabilities have already been through numerous transitions. All of these transitions involve, to some degree, an increase in the independence of the child with disabilities. The overall process of moving from dependent child to independent adult within our society is the same for all youth. That process involves families providing, over time, more opportunities for youths to make choices (and to live with, and learn from, the consequences of those choices), to take on responsibilities within the home and for self, and to engage in higher and higher levels of self-determination behaviors.

*The importance of family in the vocational rehabilitation process has been heightened by IDEA and the subsequent focus on the successful transition of students from school to work. In fact, during the last decade the family has been identified as critical to the success of transitional students as they move from school to work. For students with disabilities, family involvement during transition is not important, it is essential. Supportive families, actively involved in their young member’s transition to the world of work, greatly increase the chances for successful transitions. --26<sup>th</sup> IRI, The Family as a Critical Partner in the Achievement of a Successful Employment Outcome, 2000*

It is also assumed that the family is primarily responsible for teaching necessary life skills: self-care, household tasks and other daily living skills, money-management, and social graces and conventions. Even highly technical skills such as driving an automobile are often considered to be at least partially the responsibility of the family.

Although our educational system plays a role in providing instruction in employability skills—being on time, finishing a task, organization, neatness, etc.—our society still expects the family unit to bear the primary responsibility for providing these foundation skills for the future employment and independent living skills of youth. Many factors, of course, influence a family’s capacity to carry out these responsibilities: income, marital status, minority status, cultural background, language barriers, disabilities, family size, etc. Since disabilities occur across all segments of our society, families of youth with disabilities are subject to the same factors and influence as other families.

## Variables Influencing Families’ Participation in Transition Planning

Families benefit from contact with other parents and adults with disabilities. Through peer support, parents can learn about choices and self-determination strategies for their youth. Families who experience this kind of support may be more empowered to participate as equal partners in the transition planning process.

However, it cannot be assumed that all families come to the transition process with the benefit of long-term training and supports and positive adult mentors and models. For example, some children have complex needs requiring coordination of medical, therapeutic, and/or educational interventions. Not only may this create many educational and

developmental delays for the child, but also families may get caught up in a crisis mode of operation. It is all they can do to deal with the immediate problems. They do not feel they have the time or emotional energy to study, research, or reflect on the child’s future as an adult with a disability. The transition process can take such parents by surprise. They will need additional support and information to prepare for their child’s transition to adulthood.

Parents of youth with a recent onset of a disability must deal with emotions of grief and shock at the same time they are working through the transition process. It can be overwhelming. Parents of children with long-known disabilities may re-experience their early emotional reactions to having a child with a disability when they face the reality that their child is becoming an adult.

For other families, the search for an accurate diagnosis of the disability can be frustrating and emotionally draining. With little knowledge about the disability and strategies for accommodations, families need time to gather information and resources. The more knowledge families have about living independently with a disability, the greater their expectation for a rich quality of life for their youth.

Although families come to the transition process from many different circumstances, certain kinds of information and technical assistance from VR and the transition team are essential. This includes:

- Information about the difference between the “entitlement” system of services under IDEA and the “eligibility” system under the Rehabilitation Act.
- Information about State laws and policies regarding the age of majority and its implications for services under IDEA from the schools and for services from VR agencies.
- Information about the state VR agency, independent living centers, rehabilitation training centers, community rehabilitation providers, and other agencies and organizations—both public and private— which can provide transition services to youth with disabilities.
- Information about careers, job opportunities, and supported employment.
- Information and guidance about post-secondary education programs: colleges, community colleges, and vocational training programs.
- Information about consumer organizations of adults with disabilities.

*“The Arc ran a series of seminars on transition issues that was fabulously helpful to our family; my husband and I and our son, Paul, all three attended these sessions. They were formal presentations on a variety of subjects: VR and other adult service providers, housing options, SSI, estate planning, even entrepreneurial self-employment opportunities.”*  
*Jane Browning, Executive Director, Learning Disabilities Association of America – LDAA, speaking as a mom of a Downs Syndrome child, response to email survey.*

*“Each year my husband and I attend the National Convention of the National Federation of the Blind. Meeting blind people from so many walks of life has enabled my husband and me to see firsthand that blindness does not have to stop people from achieving what they want to achieve. This belief guides the way we bring up our daughter.”*  
*Serena’s mother (Castellano & Kosman, 1997)*

## Empowerment Strategies for Transition Team Partners

Empowerment begins with attitudes and assumptions about the capacities and potential of youth with disabilities. VR counselors, parents, teachers, job coaches, and others working with youth with disabilities in the transition process will be more successful if they embrace the following assumptions:

- Every youth with disabilities who is eligible for VR services is capable of productive employment.
- Youth with disabilities have the right to the same level and range of dreams and aspirations as non-disabled peers.
- Youth with disabilities have the same right to express adolescent needs, fears, concerns, immaturity, impulsivity, creativity and enthusiasms as non-disabled youth.
- Youth with disabilities have the same range of personality traits and characteristics as non-disabled peers.
- Not every problem, need, or difficulty youth with disabilities experience is associated with the disability.
- Youth with disabilities have the same capacity and need to recover and learn from bad choices, mistakes, and failures as non-disabled peers.
- Youth with disabilities need employed adults with disabilities as role models and mentors throughout the transition and pre-transition phase.
- The family has done the best they can with the information and resources available to them.
- Youth with disabilities need to have as much information as possible about all aspects of their specific disability or disabilities: medical, physical, educational, social, future implications, cultural, psychological, etc.

Although the transition team including the VR counselor will begin a relationship with the youth with disabilities before the student reaches the age of majority, the counselor knows, and should make clear to all involved, that adult serving systems such as VR, have a responsibility and obligation to respond to the needs and desires of the student as experienced by the student, not as interpreted by the family or by the educational or medical establishment. Simultaneously, the VR counselor needs to develop a relationship of trust and respect with the family, and solicit their input and support.

The VR counselor can help make this transition easier for all involved in early interactions with the student:

1. **Talk to the youth with disabilities directly.** Never speak around or about the student in the presence of the student. Always ask the student first for his or her opinion or preference on all subjects related to the student’s transition process. Let the student know by your actions and words that they are in charge of the transition process. For example, always ask the student first (not the parents) for information—i.e., social security number, description of the disability, name of their doctor, etc. Even if—especially if—the student does not know this information, the act of requesting it from the student puts the student and everyone else on notice that the student is ultimately

responsible for, and in charge of, their employment future and the process that leads up to it.

2. **Notice body language and non-verbal cues of the student indicating disagreement with what has been expressed by parents or other adult authorities.** Draw this out. Ask the student if he or she has more information or an opinion to express. Always show respect for the student's feelings and opinions. This will boost confidence and help develop and refine self-advocacy skills.
3. **Make clear to all parties your obligations regarding confidentiality upon the age of majority.** This needs to be addressed more than once or twice over the time of the transition process.
4. **Always ask the student for data first when making calls, setting up appointments, discussing need for information, e.g., medical records, family income, etc.** Although the student may not have the information or even the skills or maturity to provide the information, you are sending a message to the student and family that these are responsibilities that the student should begin to assume.
5. **Discuss openly and candidly, but respectfully, the procedural changes that will take place once the student has reached the age of majority.** Part of the transition planning will move naturally to a discussion of how and when a student will take responsibility for his or her own records and personal information—i.e., birth certificate, social security card, driver's license or photo ID, medical records, etc. These can also be incorporated into IEP goals and the transition plan.
6. **Speak frankly, honestly, openly, and respectfully about the youth's disability and the characteristics and needs associated with the disability.**
7. **Assess the student's general knowledge about his or her disability.** This includes specific awareness of how the disability affects the individual's functioning in the world, attitudes, self-esteem, and expectations centered on the disability.
8. **Ask parents and family members to share with their child transition stories of their own coming into adulthood and their first jobs.**
9. **Arrange for youth with disabilities and their families to have opportunities to meet adults with disabilities and interact with them as role models and mentors.** Help families learn about, and encourage attendance at, workshops, conferences or conventions, local meetings, etc. of disability consumer organizations. Help plan and organize adult speakers who are disabled for school classes or groups in which the youth with disabilities participates. Encourage IEP goals, which promote this interaction (e.g., the youth with disabilities will locate and interview three adults with disabilities, at least one of whom has the same disability as the student, and give a report on the adult's transition to adulthood and employment-- what worked for them, what didn't). This is also an essential aspect of promoting self-advocacy—youth with disabilities can learn skills by observing and interacting with empowered adults in convention and workshop settings, job shadowing, summer programs and camps which employ adult directors, counselors, and teachers with disabilities.
10. **Arrange for youth with disabilities and their families to have opportunities to meet and interact with youth disability groups and other youth with disabilities. Allowing students with disabilities more access to one another creates a sense of community and shared goals.**

11. **Understand the differences in transition needs of youth with different disabilities as verified in the data from the National Longitudinal Transition Study (1993).** Share and apply that information to the individual needs of each youth with disabilities. The VR counselor must view the youth with disabilities as a unique individual with needs and strengths who does not fit into a neat, stereotypical category. On the other hand, the counselor must also be aware of trends and documented research findings, which have implications for different transition and training needs of youth with specific types of disabilities.
12. **Ask parents if they envision their child's transition experience as the same or different from their own transition and the transition of peers with no disability.**
13. **Convey to student, family and others that good grades in school and the capacity to succeed in the school setting do not encompass all the skills and training needed to succeed in the work force.**
14. **Understand that families that have been strong advocates and actively involved in parent consumer organizations may or may not have difficulties in accepting their new role in the transition process.** Some may be excited, eager, and ready to turn over responsibility to the maturing student. For others, their role of assertive advocate has become so much a part of who they are and what they do that parents may not find it easy to let go.

## Conclusion

The importance of empowering youth with disabilities and their families in the transition process is under-girded by certain assumptions:

- Transition is a normal process for all families in our society.
- Youth with disabilities have the capacity to be productively and competitively employed in high-quality jobs and careers.
- With proper information and supports, families of youth with disabilities have the capacity to support successful transition.

Implementation of the strategies discussed in this chapter will result in youth with disabilities who can explain what they want to do, how they can attain their goals, and how others can help in that process. The principles will lead these students and their families to achieve the shared vision:

***Empowered youth with disabilities access the community of their choice to achieve their desired careers, lifelong learning, and a rich quality of life.***