Supporting Young Adults who are Deaf Blind in their Communities: A Transition Planning Guide for Service Providers, Families, and Friends

1. Preface

Transition planning is only effective if the plans that are developed reflect the abilities and aspirations of focus students. For this reason, the use of person centered planning as part of the transition process has received increased attention in the past several years. Jane Everson is a major leader in the use of person centered planning to improve the quality of transition plans for students with diverse disabilities. As the Director of the Technical Assistance Center of the Helen Keller National Center, she has applied the innovative use of person centered planning to assist young adults who have dual sensory impairments. This book reflects the combined experiences of Everson, her colleagues at the Helen Keller Center, and numerous individuals with dual sensory impairments and their families. Although the focus of the book is clearly on people with dual sensory impairments, the information that is presented throughout is applicable to a wider range of individuals who are experiencing the challenges of transition from school to adulthood.

2. General highlights of this book

- The population of young adults with dual sensory impairments is heterogeneous. This is also a low incidence population. These factors result in a specific and unique set of needs for such individuals, thus presenting difficult challenges to education and rehabilitation professionals.
- Sensory impairments may be congenital (occurring prior to birth) or may be acquired (adventitious). In addition, people can experience a combination of congenital and adventitious sensory loss. The timing and circumstances of the loss of sensory ability will affect transition planning. For example, the needs of a young person who loses sensory abilities in his teens will differ from those of someone born with sensory loss. These differences among people considered to have dual sensory impairments will clearly affect the complexity of transition planning.
- Person centered planning is a central key to effective transition planning for young people with dual sensory impairments. True person centered planning starts with the profile of the individual and builds on his or her dream for the future. This book, and in fact Everson’s work throughout the past several years is based upon a clear commitment to listening to the interests and aspirations of each unique individual as the key ingredient to effective transition services. Because person centered planning strategies (which include strategies such as MAPS and Personal Futures Planning) are effective in making the focus central to planning, they are an integral aspect of the approach to transition planning recommended in this book.
Services are best delivered in a transdisciplinary manner. This approach is characterized by sharing skills and expertise ('role release') across team members, thereby increasing the strength of the team overall and extending the application of skills to meet specific challenges. This approach applies not only to professionals from different service agencies but also includes focus students and their families and friends.

Effective implementation of transition services for this or any other group of students requires ongoing interagency planning. This is a cornerstone for effective transition planning for any young person with a disability.

For many people with dual sensory impairments, the need for an effective communication system is paramount. Helen Keller, for whom the Center is named, is an excellent example of the freedom that a communication system brings to a young person with dual sensory impairments. This publication provides numerous examples of the ways in which effective communication systems can be developed to allow people with even severe dual sensory impairments to be successful in integrated employment and community living.

People with dual sensory impairments often have complex medical needs, and an entire chapter is devoted to this topic. This provides an excellent resource for readers who may be working with someone with a sensory impairment.

3. Specific areas of excellence

The chapter entitled 'Consumers Speak Out' is a highlight of this book. Instead of reading about people with dual sensory impairments, we hear from them about their lives and their challenges. Sections written by seven different individuals with dual sensory impairments provide a rich description of the variety of experiences and aspirations of people who have been labeled deaf-blind. This chapter in particular lets the reader know that the focus of this book is on individuals, not a group with a common label. The fact that this chapter is one of the earlier chapters in the book adds to its impact.

In an equally powerful manner, the following chapter written by parents of young people with dual sensory impairments allows readers to understand the roles played by parents in the transition effort, as well as their dreams for their children and the challenges in reaching these dreams.

The liberal use of graphics from person centered planning meetings is excellent and provides a terrific set of examples of how this process is used effectively in transition planning. In this way the authors have extended the literature of person centered planning through the use of case studies. Readers who are unfamiliar with person centered planning approaches will learn through these examples. Other readers who have experience with these planning approaches will also benefit from the way the processes are applied to the particular challenge of transition planning.

The need for organizational change in the manner in which secondary schools implement educational services is addressed. This chapter includes a discussion of the need for secondary schools to support community based instruction as well as a focus on serving individuals with dual sensory impairments in inclusive regular education settings. The overall point of this chapter is the need for school administrators to have and to communicate a vision for how students with dual sensory impairments in their districts may best be educated. This chapter is an excellent resource for educators, rehabilitation professionals, and family members who are interested in what it will take to implement successful transition planning.

Everson and her invited contributors are some of the national leaders in the study of dual sensory impairments. This strong base of authorship, coupled with the liberal use of information from individuals with dual sensory impairments, creates a strong and cohesive content of the book.
• This book despite the volume of information that is presented, is very readable and is therefore accessible to a wide variety of readers. It also contains an enormous amount of highly practical information that is usable by individuals with disabilities, their families, and professionals who support them. For example the material on social security programs (SSI and SSDI) and on adult service options are presented in a clear and concise fashion.

4. Ways in which this publication could be enhanced

• A minor suggestion is to avoid referring to personal futures planning as ‘PFP’. This abbreviation may be a natural way to save space but may in fact lead the readers to believe that this is a static planning approach. The power of person centered planning is the unique flavor of each plan, based on individual challenges and aspirations, as Everson’s work throughout this book so clearly demonstrates.

5. Common threads that run through this publication

• Person centered planning is not an add-on to effective transition services. Rather, person centered planning is a central and integral aspect of effective transition services and most closely approximates what is intended in IDEA’s transition mandates that transition plans reflect the aspirations, strengths and interests of students.

• The author makes an assumption that transition to inclusive communities is the desired outcome for students. This is an essential point, as too many students continue to make a transition to sheltered workshops and other segregated programs.

• The development of effective communications strategies, which are often based on tactual communications (that is, using touch as a primary sensory modality), requires a trusting relationship between communication partners. Many of the stories of people with dual sensory impairments that are presented in this book reinforce this idea.

• Systems change for effective transition needs to begin with one person at a time. We create change by building on the rich, positive profiles of each student, listening to their dreams and aspirations for the future, and then working with them toward implementing an action plan to overcome challenges that impede progress toward the dream.

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