

Challenges in Coordinating and Managing Services and Supports in Secondary and Postsecondary Options

By Debra Hart, Karen Zimbrich, and Teresa Whelley

Issue: Current practices and policies, including differences between youth and adult service delivery systems and the lack of interagency collaboration, complicate service coordination for youth with disabilities. How can service coordination become more flexible, youth-centered, and culturally responsive?

Defining the Issue

As youth with disabilities prepare to leave secondary school, they and their families face the challenge of finding services and supports appropriate for adult life. Even youth with a strong sense of self may find the task of coordinating adult services and managing supports confusing, if not overwhelming (NCSPSES, 2000). First, they have to identify what services they want and what to call them, presumably learning new, adult services terminology along the way. Second, they have to find the services they have identified and decide how to fund them, hopefully gaining new advocacy and access skills in the process. Third, they have to know how to manage services and supports and what to do when circumstances, wants, and needs change. Individuals may gain self-determination skills, but will they ever figure out how “the system” works?

For example, arranging transportation to and from college or employment can be a complex and confusing issue. Will the student use public transportation or para-transportation? Will the student drive? Does the campus have a shuttle service? Is it accessible? Does the employer support car-pooling? Will the local vocational rehabilitation agency provide a vehicle and driver? Is the student eligible for medical transport? Each of these possibilities may require investigation into eligibility criteria, driver’s license and disability documentation requirements, application procedures, and identification of a funding source.

Even when services and supports can be located and secured, managing them still poses a significant barrier to satisfactory postsecondary options (NCSPSES, 2000). Educators, adult service agencies, and service providers face barriers to collaboration, including a lack of knowledge regarding each other’s systems as well as bureaucratic constraints resulting from long waiting lists and limited financial resources.

There is growing recognition that the complexity of service systems is an impediment to developing comprehensive, state and local service coordination for individuals with disabilities once they leave high school (Stodden & Dowrick, 1999). Federal laws and related policies have been implemented to address barriers to postsecondary education and employment for individuals with disabilities. These include the Americans with Disabilities Act of 1990, Amendments to the Rehabilitation Act of 1973 as amended by the Workforce Investment Act of 1998, and the Ticket to Work and Work Incentives Improvement Act of 1999. Additionally, in February 2001, President Bush launched the

New Freedom Initiative (NFI), a comprehensive plan to reduce barriers to full community integration for people with disabilities. In order for new and existing initiatives to be as effective as possible, they must be implemented in a coordinated, streamlined, consumer friendly, and culturally responsive manner.

Current Practice

Whereas the Individuals with Disabilities Education Act (IDEA) of 1997 requires that services for students be coordinated, the law does not specify how service coordination should be provided. Current models of service coordination described in the literature typically fall within four paradigms (**see Figure 1**).

Current practices and policies, including differences between youth and adult service delivery systems and the lack of interagency collaboration, complicate service coordination. As students with disabilities move from secondary education to postsecondary education and/or employment, the first challenge they face is the use of different terminology across various settings. The resulting confusion may prevent students and professionals from recognizing service gaps. The lack of common terms across service systems further contributes to a lack of understanding among service coordinators and poses an additional barrier to collaboration. Bureaucratically, these systems are well established and are likely to be inflexible in their approach due to their own internal processes, cultures, and histories.

Another major difference is that postsecondary services are not mandated, as they are within public education systems under IDEA 1997. Instead, they are based on eligibility determination and on availability of funding from an adult service agency. In addition, an individual may be eligible for services from more than one adult service agency, and different agencies have different rules, regulations, and eligibility requirements. Adult services are available from a myriad of service providers, with no designated coordinating agency, unlike service coordination requirements by the Local Education Agency (LEA). Without interagency partnerships, students and families, as well as adult service workers, may have difficulty planning and locating funds for needed services and supports.

Postsecondary educational institutions do not typically accept an Individualized Education Program (IEP) from a high school as documentation of a disability or an academic accommodation. However, colleges may be able to use high school testing results, if the information is current and disability-specific. For example, after consultation with the college, a student with a learning disability might submit the psycho-educational evaluation from eleventh grade as documentation of the learning disability. If a student needs additional documentation, it is the student's responsibility to obtain this information. The student's school files and medical records, if appropriate, need to be collected and maintained by the student after leaving high school. As a result, it is imperative that high school students learn self determination skills, including IEP and other record-management skills, so that they have the ability to assume responsibility for their records and for other aspects of adult life.

Finally, there are genuine gaps in services. In some human service agencies, for instance, eligibility criteria is less stringent for children/adolescents than for adults, so individuals considered to have a disability while in school may be deemed ineligible for services and supports as adults. Among other arguments (e.g., the often-cited rationale

that an agency cannot work with students until six months before they leave school), the question of adult eligibility may contribute to delays in service provision for students still in high school. This is particularly true for vocational services and supports, ideally in place a year or two before students leave school, which provide a base of experience vital to making informed decisions about potential career paths. Individuals with disabilities may find that services and supports are not available in their local community (e.g., interpreters, job coaches, and public transportation), or that services, such as individually supported jobs, do not match their interests. They may find long waiting lists for the more desirable community-based services. In addition, they will find a system in which no state or regional agency is responsible for tracking cross-system services or locating service gaps among agencies.

It is important to note that the barriers described above are exacerbated for students with more significant disabilities. These students often remain in special education programs well beyond their eighteenth birthdays. Usually, youth with significant disabilities are relegated to segregated programs while their non-disabled peers go to college or technical school, develop social networks, and start careers (Hart, Zaft, & Zimbrich, 2001). Activities provided in isolation rarely reflect individual student needs and preferences, nor do they provide the type of in-depth study and practice that allow a student to develop and pursue a chosen career path.

New federal initiatives may improve service delivery by enhancing existing and creating needed services. These include IDEA 1997, with its emphasis on creating access, participation, and progress in the general curriculum for all students; Medicaid Infra-Structure Grants to support the competitive employment of people with disabilities; One-Stop Career Centers, with employment services that are to include individuals with disabilities; and the New Freedom Initiative, with its commitment to reducing barriers to equality for Americans with disabilities. Service gaps may begin to be addressed as these initiatives are implemented.

Summary of Challenges

An examination of current practices by secondary education and adult service systems reveals challenges to service coordination that particularly affects students with complex needs, who may look to multiple agencies for a range of supports. In summary, the following (see **Figure 2**) are five major barriers to effective service coordination and management of supports.

Recommendations

To be effective, services and supports must be individualized, flexible, and supportive of consumer choice, change, and control. The following are recommendations for resolving the major barriers summarized above.

1. Build partnerships that establish interagency cooperation at state and local levels:
 - ? Research service coordination strategies that effectively build interagency partnerships, foster consumer self-determination, and are flexible enough to allow consumer choice.
 - ? Develop and implement state and local interagency teams and publicize interagency agreements that address issues related to service coordination.

- ? Establish unified policies and streamlined practices for intake and referral procedures, eligibility determination, communication, and service planning.
 - ? Develop and implement ongoing evaluation strategies to determine effectiveness of new models.
2. Develop clear and uniform mechanisms for information sharing, communication, and coordination of services and supports across agencies and audiences:
- ? Develop a state-level, Web-based clearinghouse with a searchable, online database of information on resources, services, eligibility requirements, and expected outcomes, available to consumers and families, postsecondary institutions, advocacy organizations, human service agencies, and workforce development sites. Include an "Ask the Expert" section, to allow users to post questions and receive immediate responses.
 - ? Translate information into languages spoken in the communities served by agencies, and address issues of cultural competencies important to family and community cultures.
 - ? Develop a glossary of common terms pertaining to supports and services that are consistent across secondary education, postsecondary education, and employment systems, to use in future national and state legislation.
 - ? Consider electronic formats, multimedia stories and diaries, multicultural/multilingual outreach, and other platforms for students, parents, and professionals to become proficient in the use of terms related to transition and adult service delivery. Evaluate effectiveness frequently.
 - ? Develop, promote, and consistently offer a Transition Coordinator/Specialist option for teachers in training, which meets specific certification standards, to be determined by the state department of education in coordination with adult service systems.
3. Conduct resource mapping and alignment on state and local levels:
- ? Fund demonstration grants that will research and develop effective resource mapping and alignment strategies, including creative flexible funding options, within and across systems and agencies. Conduct effectiveness evaluation and disseminate results nationally.
 - ? Support resource-brokering for postsecondary students and adults with disabilities at state and local levels. Pool case management resources of adult, medical, Vocational Rehabilitation, Department of Labor, and postsecondary educational agencies to create structures for support-brokering across disciplines.
4. Identify and develop services to address gaps:
- ? Include cross-system service gap identification as part of resource mapping.
 - ? Ensure that generic resources, including natural supports, are included.
 - ? Enlist consumers and their families to help locate and address service gaps.
 - ? Develop innovative strategies, such as time-sensitive service provision and cultural competence (defined as a set of behaviors, attitudes, and policies that promote effective cross-cultural work), to enable generically available service providers to be user friendly, culturally responsive, and knowledgeable about services that are

most desirable and most timely for individuals with disabilities.

- ? Develop policies that support provision of adult services prior to students exiting secondary education.
5. Build student- and family-professional partnerships using student- and family-centered strategies:
- ? Provide adequate information about adult options, services, and supports for planning and decision-making.
 - ? Promote empowerment through active participation in team meetings, using strategies such as person-centered planning, pre-planning meetings prior to IEP meetings, and the development of self-determination skills for youth.
 - ? Learn about the culture of families and communities and conduct outreach strategies, such as partnering with community-based minority organizations, to ensure recruitment and active participation of families of diverse cultures and linguistic backgrounds throughout the IEP process.

To prepare youth with disabilities for adult life, “service coordination” must be a flexible, youth-centered, culturally responsive process that assists individuals and family members to secure supports and services that they want and need, when they want and need them. A service coordinator, sometimes referred to as an independent support coordinator, independent broker, or personal agent, can assist individuals to develop career paths (e.g., through person-centered planning). The role of the service coordinator may also include securing and implementing support services, assisting individuals at managing their own services and supports, and providing ongoing evaluation of the effectiveness of these supports. Services should include formal and generic services, and natural supports within the youth’s family and the community at large.

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Figure 1: Current Service Coordination Models

1. Independent/dedicated: the agency providing service coordination is independent (does not provide services other than service coordination) and the service coordinator has no other role or responsibilities beyond providing coordination of services;
2. Independent/not dedicated: the agency providing service coordination is independent from service provision but the service coordinator has other responsibilities;
3. Not independent/dedicated: the agency provides service coordination *and* direct services to consumers but the service coordinator has no other role or responsibilities beyond providing coordination of services; and
4. Mixed: any combination of above three models (RTC, 2001).

Figure 2: Five Major Barriers to Effective Service Coordination and Management of Supports

1. Few partnerships establish interagency cooperation at the state and local level (Chadsey, Leach, & Shelden, 2001);
2. Mechanisms for information sharing, communication, and services and supports across agencies and audiences are uncoordinated (Johnson & Sharpe, 2000);
3. Resource mapping and alignment on state and local levels are lacking (Hart, Zimbrich, & Ghiloni, 2001);
4. Identification of service gaps and development of services to address gaps are

lacking (MnSIC, 2001); and,

5. Lack of student- and family-professional partnerships using student- and family-centered strategies (Hasazi, S., Furney, K, & DeStefano, L., 2000).