

Overview

Autism: Challenges Relating to Secondary Transition July 2004

by Eve Müller

Throughout the nation, states report unprecedented growth in the numbers of students identified with autism and other autism spectrum disorders¹ (U.S. Department of Education, 1994, 2002). As a result, states are focusing increasing attention on intervention programs for young children with autism. However, there is less attention being paid to the challenges faced by students with autism who are making the transition to post-secondary education or work. The purpose of this document is to describe the efforts of several state education agencies (SEAs) to address the needs of transition-aged students with autism, describe the major barriers to providing effective secondary transition services to this population and generate policy recommendations.

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Background & Legislation

This section provides a brief overview of the Individuals with Disabilities Education Act (IDEA) regulations pertaining to both autism and transition. It also includes information on the numbers of transition-aged students with autism and summarizes findings from the few studies that examine secondary school experiences and post-school outcomes for individuals with autism. Autism was added to the list of federal disability categories in 1990. IDEA regulations provide the following definition:

(1)(i) *Autism* means a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age 3, that adversely affects a child's educational performance. Other characteristics often associated

¹ The National Institute of Mental Health (NIMH) provides the following definition for autism spectrum disorders: "Autism spectrum disorders (ASDs), also known as Pervasive Developmental Disorders (PDDs), cause severe and pervasive impairment in thinking, feeling, language, and the ability to relate to others. These disorders are usually first diagnosed in early childhood and range from a severe form, called autistic disorder, through pervasive disorder not otherwise specified (PDD-NOS), to a much milder form, Asperger syndrome. They also include two rare disorders, Rett syndrome and childhood disintegrative disorder." This definition was downloaded on May 13, 2004 from the NIMH website at www.nimh.nih.gov/healthinformation/autismmenu/cfm.

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with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences. The term does not apply if a child's educational performance is adversely affected primarily because the child has an emotional disturbance, as defined in paragraph (b)(4) of this section.

(ii) A child who manifests the characteristics of "autism" after age 3 could be diagnosed as having "autism" if the criteria in paragraph (c)(1)(i) of this section are satisfied. [34 CFR §300.7 (b)(1)(i)]

The number of students identified with autism continues to grow exponentially. During 1992-93 (the first required reporting year for the category of autism) only 1,532 students with autism aged 12 through 21 were served under IDEA (U.S. Department of Education, 1994). This number grew to 44,322 students with autism aged 12 through 21 during the 2002-03 school year – 29 times the number identified 10 years earlier.² Although some of this growth in numbers may be attributed to the fact that it often takes several years for state data systems to accommodate changes, this certainly does not account for such extreme growth in numbers.

IDEA regulations provide the following definition for transition services:

- (a) As used in this part, *transition services* means a coordinated set of activities for a student with a disability that –
- (1) Is designed within an outcome-oriented process, that promotes movement from school to post-school activities, including postsecondary education, vocational training, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation;
 - (2) Is based on the individual student's needs, taking into account the student's preferences and interests; and
 - (3) Includes –
 - (i) Instruction;
 - (ii) Related services;
 - (iii) Community experiences;
 - (iv) The development of employment and other post-school adult living objectives; and
 - (v) If appropriate, acquisition of daily living skills and functional vocational evaluation.

(b) Transition services for students may be special education, if provided as specially designed instruction, or related services, if required to assist a student with a disability to benefit from special education. [34 CFR §300.29(a)]

According to federal regulations, a number of requirements must be met pertaining to secondary transition for each student with a disability, including students with autism. For example, starting at age 14, the individualized education program (IEP) for each student with a disability must include an annually updated statement of the transition needs of the student (e.g., participation in advanced-placement courses or a vocational education program) and beginning at age 16, a statement of needed transition services for the student must be developed, including, if

²Downloaded on March 22, 2004 from www.ideadata.org.

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appropriate, a statement of the interagency responsibilities or any needed linkages [34 CFR §300.347(b)].

Secondary transition poses unique challenges for students with autism. The National Longitudinal Transition Study–2 (NLTS2) compared transition experiences of students from all 13 federal disability categories and found that students with autism differ from students with other types of disability in a number of significant ways. For example, students with autism experience greater difficulty with social adjustment and are least likely to socialize with their peers, engage in extracurricular activities (e.g., sports or special interest groups), participate in transition planning and assume high levels of responsibility within their households (Wagner, Cadwallader et al., 2003; Wagner, Marder et al., 2003). Furthermore, although students with autism are among the most likely to be engaged in *work study* employment, they are the least likely to hold regular *paid* jobs (Wagner, Cadwallader et al., 2003).

Post-school outcomes for adults with autism and other autism spectrum disorders are often discouraging (Goode, Rutter & Howlin, 1994 as cited in Nesbitt, 2000; Howlin, 2000; Müller, Schuler, Burton & Yates, 2003). One study, for example, found that despite having the potential to work, few individuals with Asperger Syndrome were in regular employment and that even among those with formal qualifications, employment levels were disappointing and occupational status was low (Goode, Rutter & Howlin, 1994 as cited in Nesbitt, 2000). A second study found that adults with autism often experienced high levels of unemployment and under-employment,

and that lack of social skills frequently led to poor outcomes including being fired from jobs (Müller, Schuler, Burton & Yates, 2003).

Methodology

Information for this document was gathered in three phases. First, an Internet search was conducted to locate SEA initiatives that address the needs of transition-aged students with autism. Second, representatives from three states that have initiatives in place were interviewed (Illinois, Minnesota, and Rhode Island). Third, additional interviewees were selected to further explore a number of policy issues. The additional interviewees included the South Carolina State Director of Special Education, who is also the parent of an adult child with autism; North Carolina's state Autism Specialist, who works closely with the Treatment and Education of Autistic and Related Communication Handicapped Children program (more typically known as the TEACCH program); a service provider from Illinois with expertise in autism and secondary transition; and an adult with Asperger Syndrome from Oregon, who assists young adults with autism in negotiating the transition from school to post-school life.

Findings

State Education Agency Efforts

SEAs appear to be doing very little that specifically focuses on secondary transition for students with autism. A number of discrete efforts are underway, however, and three are described below.

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- Illinois has an Autism Training and Technical Assistance Project that offers, among other things, two days of team training focused on individualized education program planning and transition planning for high school-aged students. During 2002-03, approximately 30 teams participated and these teams are each expected to return to their districts and conduct at least three additional team trainings over the next few years. The Autism Training and Technical Assistance Project also offers workshops for families that include a transition component.
- Minnesota sponsors a statewide Autism Network and one or two day-long promising practices workshops, as well as shorter workshops, all of which focus on the provision of services to transition-aged students with autism. These workshops are paid for, in part, using IDEA discretionary funds set aside for low-incidence disabilities. More than 600 educators and vocational rehabilitation personnel have participated in these workshops thus far. Minnesota also distributes four mini-grants per year to schools throughout the state that provide exemplary services for transition-aged students with autism. Schools receive between \$1,500 and \$2,000 and are encouraged to generate user-friendly materials (e.g., handbooks or videotapes) with information on how to implement best practices.
- Rhode Island offers a series of two-hour autism training workshops, one of which focuses on secondary transition and vocational issues. Approximately 100 teachers and related school personnel have participated in this particular workshop. Rhode Island also has a number of informal demonstration sites and hopes to add a model high school classroom for students with autism in the coming school year – a classroom that teachers throughout the region would be encouraged to visit.

State interviewees also described local efforts to address the needs of transition-aged students with autism. For instance, one or more interviewees described the following types of services being offered at the local level:

- itinerant autism and/or transition consultants;
- transition programs that include an autism specialist as part of the staff; and
- social skills groups for students with Asperger Syndrome and other autism spectrum

disorders.

State interviewees also described comprehensive transition programs designed to meet the needs of *all* students with disabilities and noted that, in most cases, students with autism are successfully accessing these same services. As one interviewee noted, “Rarely do we do something that is solely related to one disability, such as autism.”

Barriers

Interviewees listed a wide range of barriers to effective secondary transition services for students with autism. These barriers are described below.

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Lack of Autism Expertise

All interviewees remarked on the lack of autism expertise on the part of general and special education teachers and vocational rehabilitation counselors. As one interviewee noted, “Despite the exploding numbers overall, there’s still a lack of understanding about autism.” This lack of understanding can be attributed in part to the limited availability of training resources specifically targeted to professionals who work with transition-aged students with autism. Another interviewee noted, “Even when you have the best transition specialists, they’re clamoring for information [on autism] and there’s very little out there.” High staff turnover also contributes to lack of autism expertise and results in the need for constant training and retraining.

Lack of Personnel Preparation

Interviewees agreed that autism-specific professional preparation at state institutions of higher education (IHEs) is lacking. Most interviewees reported that IHEs offer limited, if any, coursework on autism and none *require* such coursework for transition specialists. For instance, transition specialists are often unprepared to assess the social demands of particular work sites. If this type of assessment is not properly conducted, students with autism are likely to be placed in jobs where they are unable to meet the social demands and are therefore less likely to succeed. Personnel preparation is also not keeping up with the growth in numbers of students identified with autism. As one interviewee noted, referring to both special educators and vocational rehabilitation counselors who work with transition-aged students with autism, “There’s a real shortage of staff on both sides of the line.” Another interviewee noted that it is also difficult to find personnel who are qualified to teach university-level courses on the topic of autism and secondary transition (i.e., individuals with expertise in both areas).

Focus on Early Intervention

All interviewees detailed extensive efforts to provide early intervention services for young children with autism, but admitted that few dollars and/or limited programming are currently targeted to transition-aged students with autism. One interviewee assessed the status of such services as follows: “We’re doing a better job for preschool-aged children, doing okay for elementary, [but] it begins to get diluted when it gets to middle school and there’s very little out there when [students with autism] become adults.”

Invisibility of Population

Most interviewees mentioned that although the incidence of autism is very high among elementary school-aged students, the bubble has not yet reached high schools. Several warned that high schools are ill prepared to meet the needs of the many students with autism who will soon be enrolling. One interviewee expressed frustration that states only seem to be willing to budget monies for autism once the numbers have gotten out of control. He said, “I’ve been preaching this message for seven years....these kids are coming and you need to get ready. This is not a condition that kids outgrow and most secondary programs need to have more preparation

to be ready.”

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Two interviewees also noted that parents of transition-aged students with autism are less wellorganized

in terms of advocacy than are parents of younger students with autism. Without strong advocacy on their behalf, transition-aged students remain a relatively invisible population. As one interviewee noted, “It’s the squeaky wheel that gets the grease.”

Lack of Interagency Collaboration

Several interviewees noted that outside agencies, such as vocational rehabilitation, are often unwilling or unable to get involved in the transition process until a student turns 18. As one interviewee said, “The other agencies that should be involved don’t have the resources or aren’t willing to commit the resources at the level individuals with autism need in order to succeed.”

This lack of early and sustained collaboration between schools and outside agencies makes it difficult to facilitate a seamless transition to post-school life for many students with autism.

Interviewees also expressed frustration at the lack of joint training efforts, commenting on the difficulty of getting staff from vocational rehabilitation agencies to participate in such trainings.

Generic Transition Services

Several interviewees noted that the trend towards non-categorical services has sometimes resulted in a generic or one-size-fits-all approach to transition programming, making it difficult to meet the unique needs of students with autism. Interviewees were careful to add that this did not mean they support a return to categorical services, merely that it is important to provide a truly *individualized* approach to services. Several stressed that social skills training is absolutely necessary for students with autism. According to one interviewee, however, there is often a “lack of social skills training as part of the generic transition model,” an oversight which tends to have a disproportionately negative impact on students with autism.

Other interviewees noted that while movement away from categorical certification (e.g., certification of autism specialists) has contributed to more inclusive programming, this trend has also greatly reduced the number of professionals who are sensitive to the unique secondary transition needs of students with autism.

Misidentification

Two interviewees said that federal and/or state definitions of autism that do not include all autism spectrum disorders are too limited and occasionally result in misidentification. For instance, one interviewee noted that, in her state, high functioning students with Asperger Syndrome are frequently misidentified as emotionally disturbed, occasionally leading to the provision of inappropriate transition services.

Budgetary Constraints

Interviewees reported that dwindling resources at the state and local levels make it difficult to start new initiatives, hire adequate staff to provide consultation services or even maintain services at existing levels. Budget deficits also mean that the number of vocational rehabilitation

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counselors is down, negatively impacting the ability of vocational rehabilitation agencies to provide needed supports to transition-aged students with autism.

Recommendations from Interviewees

In the course of the interviews conducted for this document, each interviewee was asked for recommendations to address the barriers he or she identified. These recommendations include

the following:

- Explore the possibility of having state-level support for autism coordination and ensure that any state-level infrastructures for serving students with autism also address the needs of *older* students with autism.
- Offer professional development opportunities on the topic of autism and secondary transition that jointly serve education personnel and vocational rehabilitation counselors.
- Strengthen the legal requirements for the participation of outside agencies in transition planning (e.g., require that representatives from agencies such as vocational rehabilitation attend all transition meetings starting at a student's 14th birthday).
- Foster collaborations between SEA, vocational rehabilitation agencies and IHEs to provide social supports and accommodations for college students with autism similar to accommodations available for college students with other disabilities.
- Make social skills training available, as appropriate, for all secondary transition-aged students, including students with autism.
- Earmark state funds for transition-aged students with autism, in addition to generic funds for autism and/or secondary transition.
- Work with IHEs to ensure that information on autism is integrated into teacher training courses on secondary transition and that information on secondary transition is integrated into courses on autism.
- Encourage IHEs to require at least minimal coursework on autism for all special educators and rehabilitation counselors.
- Revise Medicaid standards to allow reimbursement of specialized supports for individuals with autism.
- Revise vocational rehabilitation regulations to allow for more than 90 days of services for individuals with autism – allotting the same number of total hours, but permitting hours to be extended over a longer period of time.
- Expand federal and/or state definitions of autism to include all autism spectrum disorders (e.g., Asperger Syndrome and PDD-NOS).
- Convene a state-level advisory panel of parents, teachers and students with autism to address the needs of transition-aged students with autism.
- Encourage the Office of Special Education and Rehabilitative Services (OSERS) to offer grants that address secondary transition for students with autism and are jointly administered by OSEP and the Department of Vocational Rehabilitation.

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Concluding Remarks

Although few resources are currently directed specifically at transition-aged students with autism, their numbers continue to grow exponentially. State and local policymakers are advised to give increased consideration to the unique needs of this rapidly growing population – ensuring that individualized services, including social skills training, are readily available to them.

Interagency collaboration is key, as is the preparation of both special education and vocational rehabilitation personnel to provide appropriate transition supports for students with autism.

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Autism on Campus: The Other Diversity

By Daniel Passantino, February 25, 2007



Personal Voice: "I spent my days as tense as a hunted animal, fearing the scornful gazes of students who shunned me like they would a person who'd committed a heinous crime."

As I walked home through Central Park one afternoon -- having been expelled from Hunter College's Manhattan dorms that morning -- I was so emotionally drained that even the bare trees seemed vivacious by comparison. During my two months as a resident student, I'd lost 15 pounds, slept maybe five hours a night, and had constant, vivid, flashbacks of my many humiliations. I spent my days as tense as a hunted animal, fearing the scornful gazes of students who shunned me as they would a person who'd committed a heinous crime. My self-esteem was shattered; when enough people look at you with disgust, it's hard not to see yourself as disgusting. As for why? The best answer I have is that, in this era of tolerance, on a campus where the mere mention of racism elicits anger, I was guilty of being different from my peers.

My most marked difference from the other students is labeled "[Asperger's Syndrome](#)" (AS). It's a milder form of autism. According to a [CDC study](#) released in February, about 1 in every 150 American children has an "Autistic Spectrum Disorder." That category includes everyone with some variant of the disability. Asperger's Syndrome, which is one of the least conspicuous conditions on the autism spectrum, doesn't alter the appearance or reduce the academic abilities of those with it -- but renders us "Aspies" unable to intuit emotions from body language. In conversations, people without social disabilities -- pejoratively called "neurotypicals" -- rely on a steady stream of unspoken social data to time their words so smoothly their entire interactions seem almost

prechoreographed. Since we Aspies don't pick up on these cues, we wind up awkwardly barging into chats, or getting sidelined out of them. Not getting much in the way of social feedback also makes us forthright to the point where many people find us offensive. The notion of dissembling to "protect" someone's feelings doesn't come naturally to us. After all, we can't understand people who aren't completely honest with us. In hindsight, my decision to enter a college dormitory -- a socially trying place for even a neurotypical -- was, to put it mildly, misguided.

At first, things went well for me at the dorms. I made lots of acquaintances there and figured I was well on my way to starting a new life as a "normal" person. Within a few days, though, I found that whenever I tried to go somewhere with the people I'd met, they'd tell me that they'd already made arrangements with their own buddies.

Barely two weeks of the semester had passed before loose bunches of students crystallized into cliques. These met all their members' needs for companionship, but left outsiders like me with few opportunities to socialize with those in them. I figured that I could solve the problem of my isolation from these groups by forming bonds with individuals. One way I tried to do this was by holding little ice-cream parties in the lounge of my dorm floor with open invitations. People came, ate my food and conversed among themselves.

My main strategy, though, was simply to ask people to go out to get coffee, see movies, or visit museums with me. When, after getting put off with "wait until next week" several times, I'd inquire about planning up to a month in advance, but my acquaintances would tell me they were still too busy, even though they were always hanging out with other people.

Instead of going places with students, I began getting summoned to meetings with the school staff where I'd be told "certain students felt threatened" by my "hanging around them," that "troubling stories" about me had been heard and that I'd been "stalking people." In hindsight, my best guess as to why this happened is that some of my classmates wanted me to stay away from them, but for fear of "hurting my feelings," had indicated their desires nonverbally rather than by rejecting me outright. As an Aspie, I don't pick up on social warning signals. Eventually the situation at the dorm worsened to the point where I was ordered out.

Social scientists have recently noted that modern, socially mobile Americans -- like college students -- tend to actively seek out groups of like-minded people. That tendency was labeled "homophily" (literally, love of the same) and is hypothesized to be based on a desire for comfort. The implications of this are disturbing for an already socially polarized country; for people with AS, they're even worse. Simply put, Aspies make most people uncomfortable. Society is so inundated with rituals of politesse that those who don't follow them are considered offensive. As a result, people like me wind up ostracized, not as a result of widespread anti-autistic hate-mongering, but simply because neurotypicals find our differences disquieting. It's bigotry by default.

The first step towards eliminating intolerance for people with Asperger's Syndrome has to be taken by Aspies. We need to be open about having the disorder. I spent a long time pretending -- even to myself -- that I wasn't autistic and could just "fit in." Of course, denying I was an Aspie didn't stop me from being one; it just prevented me from taking advantage of information about autism which could have helped me adapt to college. People at my school were left to assume that all of my differences from them were attributable to trouble-making impulses.

I think the main reason Aspies are hesitant to be open about having AS is that they see their label as a mark of shame. That was the case for me. After my expulsion from the dorms, though, that changed. I didn't embrace my Aspie identity to be courageous. It was simply that, under the circumstances, I could either agree with most of my classmates that I deserved to be excluded, or come to grips with the fact that I was different. I opted for the latter.

Nowadays I'm damned proud to be an Aspie. My bluntness may offend people, but at least I don't have to walk around feeling I'm a fake. Another typically Aspie tendency I have is to analyze issues rather than to simply emote over them. This makes me come off as "cold" sometimes, but it also often enables me to gain a deeper understanding of issues than supposedly more "insightful" neurotypicals. In essence, I approach the world as a place where problems usually have a cause that can be reasoned out with enough contemplation. The way I see it, figuring out why things happen is the first step to making them better. Finally, like many Aspies, I have "hypersensitive senses." Loud noises and bright lights pain me -- but, at the risk of sounding poetic -- I'm also able to experience the beauties of this world more vividly. Considering that Aspies' variant neurology sometimes has -- well -- benefits as well as drawbacks, I think it should be considered a form of diversity to be tolerated, not merely a disease to be stamped out. From what nonautistics have told me, I'm like a bull in a china shop when it comes to socializing. Sometimes even those close to me get tired of my breaking interpersonal taboos. However, to extend the metaphor, they don't expect me to quit being clumsy and to start tap dancing like everyone else. That's fine by me. Tolerance is about getting along more or less in harmony, not being the same.

Daniel Passantino, 19, is a sophomore currently enrolled in the Macaulay Honors College at CUNY Hunter. He lives with his parents and sister in Manhattan. As of yet he has not selected a major but hopes to find a career that will allow him to continue advocating for the disabled.

For more information on the Asperger's Syndrome, visit these sites:

<http://www.aspennj.org>

<http://www.ahany.org>

<http://www.udel/edu>

<http://www.tonyattwood.com>

Campus Career Development Services: Promoting Inclusive Practices

By:

Cynthia Zafft,
Abigail Waugh, &
[Melanie Jordan](#)

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College to Career Networks

College students with disabilities putting their education to work

1. Why Are Disability Issues Relevant to the Office of Career Development?

The Office of Career Development is for all students, with and without disabilities.

Did you know that...

- Students with disabilities make up 9.4% of the students in postsecondary education?
- You cannot always tell just by meeting someone whether they have a disability?

The Office of Career Development is the campus resource for employment preparation, career exploration, and job placement.

- The Office of Disability Services helps students locate academic and student life accommodations.
- Consulting the Office of Disability Services to find translators, accessible locations on campus, and other accommodations for students is a great idea, but the Office of Career Development is the expert on career development for all students, those with and without disabilities!

Students with disabilities have the desire and qualifications to work after they graduate, but typically they do not obtain appropriate jobs as frequently as their peers without disabilities.

- Even with a postsecondary education, only 50% of people with disabilities are employed.

The Americans with Disabilities Act of 1990 (ADA) influences the interviewing process and promotes accommodations after hiring.

- Students can request accommodations for job interviews.
- On the application and during the interview, students do not have to answer certain questions related to their disability.
- On the job, students can ask employers for reasonable accommodations. Making the Office of Career Development welcoming to everyone is easy.
- A few simple, inexpensive changes can make the Office of Career Development more inclusive for all students.
- Taking a moment to learn about disability etiquette and accessibility can help the Office of Career Development serve students even better!

To learn more...

- [The Disability Exchange - www.disabilityexchange.org](http://www.disabilityexchange.org)
- [Chartbook on Work and Disability - www.infouse.com/disabilitydata/workdisability.html](http://www.infouse.com/disabilitydata/workdisability.html)
- [Women with Disabilities - www.4women.gov/wwd](http://www.4women.gov/wwd)

2. Career Planning and the Americans with Disabilities Act: The Basics

What is the Americans with Disabilities Act?

The Americans with Disabilities Act (ADA) mandates that people with disabilities have freedom, equality, and the opportunity to participate in public life.

What does the ADA mean for employment?

Title I of the ADA requires that accommodations be made so that qualified individuals with disabilities have access to the same employment opportunities as individuals without disabilities.

How does the ADA influence the application and interviewing process?

Students should be able to access application materials in alternative formats and ask for accommodations, such as a sign language interpreter, during an interview. Employers cannot ask interviewees about their health or disabilities. They can only ask questions that directly relate to the individual's ability to do the job.

What is a "reasonable" accommodation?

There is no easy definition of a "reasonable" accommodation.

Employers should consider each request individually. Employers are only required to make an accommodation if an employee requests one. Employers are not required to suffer "undue hardship," such as extreme cost or diminished production standards, to accommodate an employee. Accommodations may be requested at any time during the period of employment.

Does the ADA require that people with disabilities automatically get hired?

No, the Americans with Disabilities Act does not require employers to hire people with disabilities. Individuals should be qualified for the position and be able to perform the essential job functions with or without accommodations.

To learn more...

- [The United States Department of Justice - www.usdoj.gov/crt/ada/learnada.htm](http://www.usdoj.gov/crt/ada/learnada.htm)
- [The United States Equal Employment Opportunity Commission - www.eeoc.gov/ada/adahandbook.html](http://www.eeoc.gov/ada/adahandbook.html)

3. The ADA and the Job Application Process

Job applicants have the right to ask for a reasonable accommodation at any time during the application process. This includes help with filling out a job application and any accommodations needed for the job interview.

Under the ADA, potential employers cannot ask questions that would cause an applicant to disclose information about a disability in a job interview. Here are some examples of questions that are not allowed.

Illegal questions:

- Do you have a disability or medical condition?
- Have you ever been hospitalized?
- Do you take prescription drugs?
- Have you ever been treated for a drug or alcohol problem?
- Did you receive worker's compensation from your last job?
- What is your HIV status?

Potential employers are allowed to ask questions about an applicant's ability to perform essential job functions. Here are some examples of questions that are permitted:

Allowable questions:

- Can you perform the essential duties of the job, with or without reasonable accommodations?

- Can you tell me (or demonstrate) how you will perform these duties?
- Can you meet the attendance requirements of the job?

About medical examinations

Employers may not require a medical exam before a job has been offered. They may require physical exams once a job has been offered, but only if they require the exam of all new employees. Tests to assess current illegal drug use are not considered "medical examinations" under the ADA and are permissible as long as all applicants are subject to the same requirement.

Preparing for an interview

Unfortunately, potential employers may not be aware of all ADA regulations. Students might want to role-play their responses to illegal interview questions. This will help students learn how to emphasize their strengths during interviews, without revealing unnecessary information about their disabilities.

To learn more...

- [BT.Novations on the ADA - www.btweb.com/ADAInfluence.asp](http://www.btweb.com/ADAInfluence.asp)
- [University of Wisconsin Milwaukee - www.uwm.edu/Dept/HR/refmaterial/adayou/vol4num2.htm](http://www.uwm.edu/Dept/HR/refmaterial/adayou/vol4num2.htm)

4. Are you accessible?

Making the Office of Career Development accessible to students with disabilities may seem like a challenging task. You may wonder whether you have the time or budget to accomplish this. While it may take several years to make your office completely accessible to students with disabilities, there are some simple things you can do quickly and inexpensively. Small changes can make a big difference!

Steps towards inclusion:

- Post a sign in your office that says, "Let us know if we can help you in any way." By announcing this to students as they enter the Office of Career Development, it lets them know your office is welcoming to all students.
- Make sure the lighting in your office is adequate. This is useful for students who are reading lips and students with visual disabilities.
- Avoid using any fragranced products in the office. Some individuals are highly sensitive to such scents.
- Advertise events in multiple ways, such as email, flyers, and announcements on the school radio station. By spreading the word using different methods, you will reach more students.
- Create a checklist for events that incorporates accessibility issues.

This will be a useful reminder as you plan events.

- Create a process that will allow students to request necessary accommodations, and ensure that students know how to request such accommodations. Designate a staff member to be in charge of accommodation requests. Post "accommodations available upon request" on all brochures and fliers.
- Have resources available to provide accommodations when they are requested. This would include the capacity to put printed information into alternative forms, such as audiotape or digital text. It is also useful to have the contact information of several qualified American Sign Language interpreters.
- Have a public address system at your events. This will help your audience hear the speaker, especially people who are hard of hearing.
- Use physically accessible locations on campus for your programs. Keep in mind that newer buildings tend to be the most accessible.
- Have an inclusive attitude. An open mind makes you accessible to students with disabilities!

To learn more...

- [The United States Access Board - www.access-board.gov](http://www.access-board.gov)
- [National Center on Workforce and Disability/Adult, "Designing access for all" - www.onestops.info/category.php?cat_id=4](http://www.onestops.info/category.php?cat_id=4)

5. Building a Connection: Basic Disability Etiquette

Being respectful:

- Use your normal tone and vocal strength.
- Speak directly to the student, even if an interpreter is present.
- Ask before helping someone.
- If you are unclear about something a student has said, just ask for a clarification.

Thoughtful language:

- Use person-first language. *For example, use "a student with a disability," instead of "a disabled student."*
- Avoid judgmental language. *Say "uses a wheelchair," instead of "wheelchair-bound."*
- Avoid cliches about disabilities. *Make your point without relying on such phrases as "the blind leading the blind."*

Everyone is different:

- Students with disabilities, just like students without disabilities, all come to you with different life experiences and differing needs from the Office of Career Development. *Even students who have similar disabilities*

have different needs. Asking is more helpful than assuming.

To learn more...

- [National Center on Workforce and Disability/Adult, "Disability: the basics" - www.onestops.info](http://www.onestops.info)

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www.communityinclusion.org

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Career Preparatory Experiences

National Alliance for Secondary Education and Transition

Supporting Evidence & Research

The Career Preparatory Experiences standards and indicators are based on sound evidence and research that supports their utility in the field. The information below identifies and presents research, federal government documents, commissioned reports, and other sources that serve as the foundation upon which these standards are based. This compilation should not be viewed as all-inclusive, but rather as illustrative of the range of research and expert analysis currently available.

Youth Benefit from Career Preparatory Activities in Schools and Communities

Several positive academic and vocational effects are attributed to school-based career development—specifically, career advising and curriculum-based interventions such as computer-based career guidance. These positive effects include higher grades, better relationships with teachers, increased career planning, greater knowledge of careers, improved self-esteem, improved self-knowledge, and less career indecision (Hughes & Karp, 2004; Lapan, Gysbers, & Sun, 1997).

Participating in Career and Technical Education (CTE) results in short- and medium-term earning benefits for most students at both the secondary and postsecondary levels and increased academic course taking and achievement by students, including students with disabilities (Castellano, Stone, Stringfield, Farley, & Wayman, 2004; Plank, 2001; Stone & Aliaga, 2003). Those who complete both a strong academic curriculum and a vocational program of study (*dual concentrators*) may have better outcomes than those who pursue one or the other (Silverberg, Warner, Fong, & Goodwin, 2004; Plank, 2001; Stone & Aliaga, 2003). CTE participants are more likely to graduate from high school (Schargel & Smink, 2001; Smink & Schargel, 2004), be employed in higher paying jobs, and enroll in postsecondary education (Hughes, Bailey, & Mechur, 2001).

The Workforce Investment Act (WIA) of 1998 reinforces the need for career preparatory experiences for all youth. WIA services include: (a) comprehensive career development services based on individualized assessment and planning, (b) youth connections and access to the

One-Stop career center system, and (c) performance accountability focused on employment.

While work experiences are beneficial to all youth, they are particularly valuable for youth with disabilities (Blackorby & Wagner, 1996; Colley & Jamison, 1998; Kohler, 1993; Kohler & Rusch, 1995; Luecking & Fabian, 2000; Mooney & Scholl, 2004; Morningstar, 1997; Rogan, 1997; Wehman, 1996). Youth who participate in occupational education and special education in integrated settings are more likely to be competitively employed than youth who have not participated in such activities (Blackorby & Wagner, 1996; Colley & Jamison, 1998; Luecking & Fabian, 2000; Mooney & Scholl, 2004; Rogan, 1997).

Activities in School-Based and Community Settings

Standard 2.1

Youth participate in career awareness, exploration, and preparatory activities in school- and community-based settings.

Career preparation components that are related to positive secondary and postsecondary school outcomes include: (a) opportunities for both school-based and community-based experiences that expose youth to a broad array of career paths, experiences, and occupations; (b) opportunities for youth to build relevant skills, academic knowledge, and personal competencies required in the workplace and for continued education; and (c) opportunities for youth to tailor their career experiences to meet their individual needs (American Youth Policy Forum & Center for Workforce Development, 2000; Castellano, Stringfield, Stone & Lewis, 2002).

School-based and community-based career preparatory activities provide the skills and knowledge young people need to make more informed decisions, to progress toward postsecondary education, and to be successful in a career (National Commission on the High School Senior Year, 2001). Career preparatory activities also provide youth with the opportunity to test academic theories through real-world applications (Partnership for 21st Century Skills, 2003). Contextual learning is at the core of career preparatory activities; community-based learning helps youth to build upon their life experiences and apply existing knowledge at the workplace (Pierce & Jones, 1998). Additionally, such activities allow students to see the practical value of the high school curriculum (National Research Council & Institute of Medicine, 2004).

Quality career development goes beyond simple academic or vocational guidance to help align academic experiences with student interests and strengths, learning preferences, and education goals. Through activities such as career awareness in the elementary years and career exploration in secondary grades, youth not only learn about a variety of careers and occupations but also begin to identify the skills required to succeed in these areas, allowing them to make better-informed career decisions (American Youth Policy Forum & Center for Workforce Development, 2000; Castellano, Stringfield, Stone & Lewis, 2002).

Integrated Career Development Activities

Standard 2.2

Academic and non-academic courses and programs include integrated career development activities.

Effective career development approaches that integrate academic and non-academic components include:

- 1 A process for career planning and goal setting (Benz, Yovanoff, & Doren, 1997; Goldberger, Keough, & Almeida, 2001),
- 2 Alignment of school-based career preparatory experiences with employer and occupational requirements and with postsecondary education plans (Bremer & Madzar, 1995; Carnevale & Desrochers, 2003; Haimson & Bellotti, 2001), and
- 3 Teaching of basic skills needed for career success and growth (Haimson & Bellotti, 2001; Luecking & Fabian, 2000; Phelps & Hanley-Maxwell, 1997).

Meaningful School- and Community-based Work Experiences

Standard 2.3

Schools and community partners provide youth with opportunities to participate in meaningful school- and community-based work experiences.

Through partnerships with employers, schools are able to provide a range of learning experiences for students. Nearly 55% offer job shadowing, 44% offer co-op programs, 40% provide school-based enterprises, 35% provide mentoring activities, and 34% offer student internships (Medrich, Ramer, Merola, Moskovitz, & White, 1998). With the number of school/employer partnerships on the rise, participating businesses are now recognizing that improved work-based learning for youth means better-prepared future employees, reduced recruitment

costs for firms, and reduced employee turnover (Wills, 1998).

Components of meaningful school- and community-based work experiences include high-quality work experiences, careful planning to match work experiences with each youth's interests and assets, linkages between work experience and academic content or school curriculum, and individual supports and accommodations (American Youth Policy Forum & Center for Workforce Development, 2000; Benz et al., 1997; Bremer & Madzar, 1995; Colley & Jamison, 1998; Goldberger et al., 2001; Haimson & Bellotti, 2001; Luecking & Fabian, 2000; Mooney & Scholl, 2004; Phelps & Hanley-Maxwell, 1997; Scholl & Mooney, 2005).

Acquisition of Employability and Technical Skills, Knowledge, and Behaviors

Standard 2.4

Schools and community partners provide career preparatory activities that lead to youths' acquisition of employability and technical skills, knowledge, and behaviors.

Work-based learning is an integral part of the academic curriculum, reinforcing academic and occupational skills learned in the classroom, providing career exploration and a broad understanding of an occupation or industry, motivating students, introducing generic workplace skills, and teaching entry-level technical skills (American Youth Policy Forum & Center for Workforce Development, 2000). Working closely with employers allows schools to define the knowledge and skills necessary for graduates to successfully perform in college and the workplace (Achieve, 2004).

Through formal and informal work-based learning, students begin to apply academic knowledge to workplace settings and gain greater respect for and facility in the types of learning required by the workplace. Students acquire skills and develop attitudes that are critical to on-the-job success, including (a) an understanding that learning often is related to a clear and meaningful goal, (b) the need for quality and the consequences of compromised quality, (c) critical thinking, (d) different approaches to problem-solving, (e) the importance of immediate feedback for learning and improvement, (f) improved skills for working in teams, (g) appreciation of the importance of deadlines, and (h) a higher motivation to examine a particular subject more deeply (Center for Workforce Development, 1998).

Strategies leading to the acquisition of employability and technical knowledge, skills, and attitudes include:

- 1 Instruction in employability skills (Bremer & Madzar, 1995; Kohler, 1994; Phelps & Hanley-Maxwell, 1997);
- 2 Assessments of career interests and abilities (Bailey & Hughes, 1999; Hamilton & Hamilton, 1997; Phelps & Hanley-Maxwell, 1997),
- 3 Exposure to and understanding of workplace expectations and conditions (Luecking & Fabian, 2000; Phelps & Hanley-Maxwell, 1997);
- 4 Life skills instruction and development in areas such as self-determination, self-evaluation, planning, and social-behavioral skills (Kohler, 1994; Phelps & Hanley-Maxwell, 1997); and
- 5 Job-seeking activities (Phelps & Hanley-Maxwell, 1997).

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Other Resources:

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Pathways to Success: St. Louis Community College, Meramec

Pathways to Success is a 3 or 4 semester series of non-credit courses for individuals interested in developing and sharpening skills in preparation for entering the workforce as well as engaging in personal growth. Upon successful completion of the program's requirements, students will earn a certificate of Workplace Readiness from St. Louis Community College.

Students who will benefit from this program include high school graduates in need of an alternative to traditional college-level academics, as well as students who may have or might struggle with completing college preparatory or developmental courses on the credit side of the college.

Certificate program courses are offered through Continuing Education, and draw from three essential areas of personal, academic and workplace-readiness development: communication skills, life skills and career skills.

- **Communication Skills** courses focus the student on the reading, writing, speaking, listening and critical thinking skills necessary for workplace and interpersonal communication at an informed level.
- **Life Skills** courses optimize the student's facility with coping strategies necessary for independent living, through exploration of financial, consumer, health and personal development issues in an applied framework.
- **Career Skills** courses focus on the development of skills necessary for workplace settings, and include job application, interviewing, workplace soft skills, and resume building skills through effective identification and employment of appropriate business behaviors and attitudes.

Students are required to take 2 Communication Skills courses, 2 Life Skills courses and 4 Career Skills courses in partial fulfillment of the Workplace Readiness certificate. Additionally, students must enroll in the cornerstone course, CPDV: 150: *Exploring Employment*, during their first semester, as well as the capstone course, CPDV 160: *Gateway Portfolio*, near the end of the program. Following completion of coursework, students must complete a minimum two-month internship, wherein students apply skills learned in the program to a workplace setting,

First Semester Course Schedule:

Computer Fundamentals: Comp: 701:600;	M/W	1:00-2:15 PM
Fundamentals of Communication: Comm: 718:600	M/W	2:30-3:45 PM
Workplace Communication: BUSN:713:600	M/W	4:00-5:15 PM
Exploring Employment: CPDV:701:600	T/Th	2:00-3:15 PM
You and Your Money: FINC:704:600	T/Th	3:30-4:45 PM

Course costs are \$159.00 per class, this does not include the cost of textbooks. Semester start dates: Fall 2009: Oct 5 – December 15, 2009

Spring 2010: Jan 25- May 17th, 2010

For more information, or to register for the program, please contact the program coordinator:

Ann Marie Schreiber , 314.984.7704 or aschreiber@stlcc.edu.

Issue Brief

Examining Current Challenges in Secondary Education and Transition



National Center on Secondary Education and Transition

Creating Opportunities for Youth
With Disabilities to Achieve
Successful Futures

A partnership of —

Institute on Community Integration,
University of Minnesota,
Minneapolis, Minnesota

National Center for the Study
of Postsecondary Education
Supports (RRTC), University
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National Association of State
Directors of Special Education,
Alexandria, Virginia

U.S. Department of Education,
Office of Special Education
Programs, Washington, D.C.

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 (National Center for the Study of Postsecondary Educational Supports [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 (NCSPES, 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, 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 inter-agency 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

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 (Research and Training Center on Service Coordination, 2001).

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 Infrastructure 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 affect students with complex needs, who may look to multiple agencies for a range of supports. In summary, there are five major barriers to effective service coordination and management of supports (see **Figure 2**).

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 in **Figure 2**.

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

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 (Minnesota System of Interagency Coordination, 2001); and,
5. Lack of student- and family-professional partnerships using student- and family-centered strategies (Hasazi, Furney, & DeStefano, 2000).

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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Key Provisions on Transition IDEA 1997 compared to H.R. 1350 (IDEA 2004)

On December 3, 2004, President George W. Bush signed H.R. 1350 (IDEA 2004) into law. This document identifies the major differences between IDEA 1997 and H.R. 1350 (IDEA 2004) concerning transition services (**bold** text indicates language changes from IDEA 1997).

Individuals with Disabilities Education Act of 1997	H.R. 1350: Individuals with Disabilities Education Improvement Act of 2004
Part A: GENERAL PROVISIONS	
Section 601: SHORT TITLE; TABLE OF CONTENTS; FINDINGS; PURPOSES	Section 601: SHORT TITLE; TABLE OF CONTENTS; FINDINGS; PURPOSES
<p>(d) PURPOSES. The purposes of this title are—</p> <p>(1)(A) to ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for employment and independent living</p>	<p>(d) PURPOSES. The purposes of this title are—</p> <p>(1)(A) to ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living</p>
Section 602: DEFINITIONS	Section 602: DEFINITIONS
<p>(30) TRANSITION SERVICES. The term “transition services” means a coordinated set of activities for a student with disability that—</p> <p>(A) is designed within an outcome-oriented process, which promotes movement from school to post-school activities, including post-secondary education, vocational training, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation;</p> <p>(B) is based upon the individual student’s needs, taking into account the student’s preferences and interests; and</p> <p>(C) includes instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and when appropriate, acquisition of daily living skills and functional vocational evaluation.</p>	<p>(34) TRANSITION SERVICES: The term “transition services” means a coordinated set of activities for a child with a disability that—</p> <p>(A) is designed to be within a results-oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child’s movement from school to post-school activities, including post-secondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation;</p> <p>(B) is based on the individual child’s needs, taking into account the child’s strengths, preferences, and interests; and</p> <p>(C) includes instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and when appropriate, acquisition of daily living skills and functional vocational evaluation.</p>

**Individuals with Disabilities
Education Act of 1997**

**H.R. 1350: Individuals with Disabilities
Education Improvement Act of 2004**

Part B: ASSISTANCE FOR EDUCATION OF ALL CHILDREN WITH DISABILITIES

**Section 614: INDIVIDUALIZED
EDUCATION PROGRAMS**

(c) ADDITIONAL REQUIREMENTS FOR
EVALUATION AND REEVALUATIONS

(5) EVALUATIONS BEFORE CHANGE IN
ELIGIBILITY—A local educational agency shall
evaluate a child with a disability in accordance with
this section before determining that the child is no
longer a child with a disability.

**Section 614: INDIVIDUALIZED
EDUCATION PROGRAMS**

(c) ADDITIONAL REQUIREMENTS FOR
EVALUATION AND REEVALUATIONS

(5) EVALUATIONS BEFORE CHANGE IN
ELIGIBILITY—

(A) IN GENERAL – **Except as provided in sub-
paragraph (B)**, a local educational agency shall
evaluate a child with a disability in accordance
with this section before determining that the child
is no longer a child with a disability.

(B) EXCEPTION—

**(i) IN GENERAL – The evaluation described in
subparagraph (A) shall not be required before
the termination of a child’s eligibility under this
part due to graduation from secondary school
with a regular diploma, or due to exceeding the
age eligibility for a free appropriate public edu-
cation under State law.**

**(ii) SUMMARY OF PERFORMANCE – For a
child whose eligibility under this part terminates
under circumstances described in clause (i), a lo-
cal education agency shall provide the child with
a summary of the child’s academic achievement
and functional performance, which shall include
recommendations on how to assist the child in
meeting the child’s postsecondary goals.**

**Section 614, INDIVIDUALIZED
EDUCATION PROGRAMS**

(d) INDIVIDUALIZED EDUCATION
PROGRAMS

(1) DEFINITIONS

(A) INDIVIDUALIZED EDUCATION
PROGRAM

(vii)(I) beginning at age 14, and updated annually,
a statement of the transition service needs of the
child under the applicable components of the

**Section 614, INDIVIDUALIZED
EDUCATION PROGRAMS**

(d) INDIVIDUALIZED EDUCATION
PROGRAMS

(1) DEFINITIONS

(A) INDIVIDUALIZED EDUCATION
PROGRAM

**(VIII) beginning not later than the first IEP to
be in effect when the child is 16, and updated
annually thereafter—**

**Individuals with Disabilities
Education Act of 1997**

**H.R. 1350: Individuals with Disabilities
Education Improvement Act of 2004**

child's IEP that focuses on the child's courses of study (such as participation in advanced-placement courses or a vocational education program);

(II) beginning at age 16 (or younger, if determined appropriate by the IEP Team), a statement of needed transition services for the child, including, when appropriate, a statement of the interagency responsibilities or any needed linkages; and

(III) beginning at least one year before the child reaches the age of majority under State law, a statement that the child has been informed of his or her rights under this title, if any, that will transfer to the child on reaching the age of majority under section 615(m); and

(viii) a statement of—

(I) how the child's progress toward the annual goals described in clause (ii) will be measured; and

(II) how the child's parents will be regularly informed (by such means as periodic report cards), at least as often as parents are informed of their nondisabled children's progress of—

(aa) their child's progress toward the annual goals described in clause (ii); and

(bb) the extent to which that progress is sufficient to enable the child to achieve the goals by the end of the year.

(aa) appropriate measurable postsecondary goals based upon age appropriate transition assessments related to training, education, employment, and, where appropriate, independent living skills;

(bb) the transition services (including courses of study) needed to assist the child in reaching those goals; and

(cc) beginning **not later than** 1 year before the child reaches the age of majority under State law, a statement that the child has been informed of the child's rights under this title, if any, that will transfer to the child on reaching the age of majority under section 615(m).

(ii) RULE OF CONSTRUCTION — nothing in this section shall be construed to require —

(I) that additional information be included in a child's IEP beyond what is explicitly required in this section; and

(II) the IEP Team to include information under 1 component of a child's IEP that is already contained under another component of such IEP.

[Note: The following text appears in Part B, Section 614 (d)(1)(A)(i), as part of the definition of what an IEP includes.]

(II) a statement of measurable annual goals, including **academic and functional goals**, designed to—

(aa) meet the child's needs that result from the child's disability to enable the child to be involved in and **make** progress in the general education curriculum; and

(bb) meet each of the child's other educational needs that result from the child's disability;

(III) a description of how the child's progress toward meeting the annual goals described in subclause (II) will be measured and when periodic reports on the progress the child is making toward meeting the annual goals (such as through the use of quarterly or other periodic reports, concurrent with the issuance of report card) will be provided;

<p align="center">Individuals with Disabilities Education Act of 1997</p>	<p align="center">H.R. 1350: Individuals with Disabilities Education Improvement Act of 2004</p>
<p>(3) DEVELOPMENT OF IEP—</p> <p>(A) IN GENERAL – In developing each child’s IEP, the IEP Team, subject to subparagraph (C), shall consider –</p> <p>(i) the strengths of the child and the concerns of the parents for enhancing the education of their child; and</p> <p>(ii) the results of the initial evaluation or most recent evaluation of the child.</p>	<p>(3) DEVELOPMENT OF IEP—</p> <p>(A) IN GENERAL – In developing each child’s IEP, the IEP Team, subject to subparagraph (C), shall consider –</p> <p>(i) the strengths of the child;</p> <p>(ii) the concerns of the parents for enhancing the education of their child;</p> <p>(iii) the results of the initial evaluation or most recent evaluation of the child; and</p> <p>(iv) the academic, developmental, and functional needs of the child.</p>
<p>(6) CHILDREN WITH DISABILITIES IN ADULT PRISONS—</p> <p>(A) IN GENERAL – The following requirements do not apply to children with disabilities who are convicted as adults under State law and incarcerated in adult prisons:</p> <p>(i) The requirements contained in section 612(a)(17) and paragraph (1)(A)(v) of this subsection (relating to participation of children with disabilities in general assessments.)</p> <p>(ii) The requirements of subclauses (I) and (II) of paragraph (1)(A)(vii) of this subsection (relating to transition planning and transition services), do not apply with respect to such children whose eligibility under this part will end, because of their age, before they will be released from prison.</p>	<p>(7) CHILDREN WITH DISABILITIES IN ADULT PRISONS—</p> <p>(A) IN GENERAL – The following requirements shall not apply to children with disabilities who are convicted as adults under State law and incarcerated in adult prisons:</p> <p>(i) The requirements contained in section 612(a)(16) and paragraph(1)(A)(i)(VI) (relating to participation of children with disabilities in general assessments).</p> <p>(ii) The requirements of items (aa) and (bb) of paragraph (1)(A)(i)(VIII) (relating to transition planning and transition services), do not apply with respect to such children whose eligibility under this part will end, because of such children’s age, before such children will be released from prison.</p>

RESOURCES

Council for Exceptional Children (CEC) <http://www.cec.sped.org/>
CEC provides a summary of the law, their recommendations, and a link to the text of the law.

National Association of State Directors of Special Education (NASDSE) <http://www.nasdse.org/>
NASDSE has a side-by-side comparison of IDEA ‘97 and the new law available for purchase.

Wrightslaw, IDEA 2004
<http://www.wrightslaw.com/law/ideal/index.htm>
Wrightslaw provides information on changes in the law, as well as some brief explanatory comments.

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Web resources regarding Person Centered Planning

Person Centered Practices

<http://www.reachoflouisville.com/personcentered/whatisperson.htm>

The Person Centered Planning Educational Site

<http://www.ilr.cornell.edu/ped/tsal/Enable/>

Inclusion Press on Person Centered Planning

<http://www.inclusion.com/PI-PERSON.C.PLANNING.html>

A Resource List on Person Centered Planning (Allen, Shea & Assoc)

<http://www.allenshea.com/resource.html>

Person Centered Planning (ARC, Michigan) overview & questionnaire

http://www.arcmi.org/person-centered_planning.htm

Ideal Lives

<http://www.ideallives.com/planning.htm>

The COMMITTEE PCP Guide for Building Healthy Social & Sexual Relationships

<http://www.w3ddesign.com/committee/guide.html>

CBI Consultants on Person Centered Planning

<http://www.cbiconsultants.com/about-traditionalvspersoncentered.html>

Person Centered Planning taken to another level (Jeff Strully)

<http://www.jaynolan.org/pcpjeff.html>

General Articles of Interest by Michael Smull

<http://www.nwtdt.com/pcp/pcparticles.htm>

Postsecondary Education Options for Students with Intellectual Disabilities

Research to Practice - Issue #45

By:

[Debra Hart](#)

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By Debra Hart, Meg Grigal, Caren Sax, Donna Martinez, and Madeleine Will

Introduction

Exiting high school is an exciting and tense experience for all students and families. But when students with intellectual disabilities consider what will happen next, the possibility of college is usually not promoted as a viable option. This needs to change. Receiving a college education and experiencing that very exciting time in life is as beneficial for students with intellectual disabilities as for students without. The growth that students experience in college can be measured in a number of areas, including academic and personal skill-building, employment, independence, self-advocacy, and self-confidence. For students with intellectual disabilities, this growth is also reflected in increased self-esteem when they begin to see themselves as more similar to than different from their peers without disabilities. Being part of campus life, taking classes (whether auditing or for credit), and learning to navigate a world of high expectations develops the skills needed for successful adult life. When we keep college in the mix of possibilities as students with intellectual disabilities explore which steps to take after high school, it makes the statement that we believe in their potential for success.

This brief presents the following information about postsecondary education for students with intellectual disabilities:

- Definitions of "postsecondary education" and "intellectual disability"
- An overview of postsecondary education options
- Research findings on current knowledge of postsecondary education options and outcomes, with recommendations for improving access

- to postsecondary education
- A bibliography, including a list of websites

Overview of Postsecondary Models

Some local school systems nationwide partner with two- and four-year public and private colleges to offer dual enrollment options to students with intellectual disabilities, age 18 and over, who are still receiving services from their school system under IDEA. There are an estimated 2000-3000 students with intellectual disabilities annually who are eligible for PSE options. Parents and local school systems typically initiate interest in pursuing these options, while local school system personnel coordinate student services. Some options are linked to teacher or rehabilitation professional preparation programs at the host institution, and participants from these degree programs provide a range of supports to students with intellectual disabilities. Very few PSE programs offer dorm experiences. Often, services end when the student ages out of public school, most often at age 21 or 22.

There are **three main types of PSE models**: mixed or hybrid, substantially separate, and totally inclusive. Within each model, a wide range of supports and services is provided. Each model is described in the order of prevalence.

- 1 **Mixed/hybrid model**: Students participate in social activities and/or academic classes with students without disabilities (for audit or credit) and also participate in classes with other students with disabilities (sometimes referred to as "life skills" or "transition" classes). This model typically provides students with employment experience on- or off-campus.
- 2 **Substantially separate model**: Students participate only in classes with other students with disabilities (sometimes referred to as a "life skills" or "transition" program). Students may have the opportunity to participate in generic social activities on campus and may be offered employment experience, often through a rotation of pre-established employment slots on- or off-campus.
- 3 **Inclusive individual support model**: Students receive individualized services (e.g., educational coach, tutor, technology, natural supports) in college courses, certificate programs, and/or degree programs, for audit or credit. The individual student's vision and career goals drive services. There is no program base on campus. The focus is on establishing a student-identified career goal that directs the course of study and employment experiences (e.g., internships, apprenticeships, work-based learning). Built on a collaborative approach via an interagency team (adult service agencies, generic community services, and the college's disability

support office), agencies identify a flexible range of services and share costs.

Fewer programs that serve adults or youth age 21 and older fall within these three models and offer the same range of services. The major difference between dual enrollment and adult PSE options is that the local education system no longer participates in providing student supports. Primarily, the student and family maintain momentum. Efforts are supported financially in the following ways.

- **IDEA funds:** Dual enrollment programs are often funded by the school system using IDEA or local school district funds. Additionally, the higher education institution can waive tuition.
- **Vocational Rehabilitation (VR):** If student's coursework is directly related to accessing employment, state VR funds might be used. Additionally, some VR agencies may offer a tuition waiver for eligible students.
- **Family funds:** PSE options can be paid for by students' families. Students without a standard high school diploma are not eligible to apply for financial aid, nor can their families use college savings or 529 plans to pay tuition and fees. This limits access for economically challenged students.
- **Other rehabilitation organizations:** State developmental disability/mental retardation departments may provide funding to assist a student with intellectual disabilities to access PSE.
- **Scholarships:** Foundations or organizations can give scholarships to students enrolling in PSE regardless of their financial or disability status, providing the student meets other requirements. Individual colleges also award annual scholarships based on demonstrated financial need.
- **AmeriCorps programs:** Funded by the Corporation for National and Community Service, these programs provide an education award or stipend to participants who volunteer for one or two years.
- **Plans for Achieving Self-Support (PASS Plans):** PASS Plans were developed by the Social Security Administration as an incentive to encourage individuals who receive Supplemental Security Income (SSI) or Supplemental Security Disability Income (SSDI) to enter the workforce. This plan allows an individual to work and save money without being penalized with a deduction from their SSI or SSDI check. There are restrictions on how the saved money can be used, but college tuition and fees would be permissible if shown to relate to a career goal and outcome.

Definitions

Postsecondary Education (PSE)

Education after the high-school level. Options for students with intellectual disabilities include community colleges, four-year colleges and institutions, vocational-technical colleges, and the other various forms of adult education.

Intellectual Disability

Refers to students with significant learning, cognitive, and other conditions (e.g., mental retardation), whose disability impacts their ability to access course content without a strong system of educational supports and services. These are not students who would access the postsecondary education system in a typical manner; rather, they require significant planning and collaboration to provide them with access. This population typically (though not always) includes students who (a) take the alternative state assessment; (b) exit secondary education with an alternative diploma, such as IEP diploma or a certificate of attendance, instead of a typical high school diploma; and (c) qualify to receive services under the Individuals with Disabilities Education Act (IDEA) until they are 21.

Research

Of all students with disabilities, those with intellectual disabilities have the poorest post-school outcomes. Until recently, the option of attending college, especially the opportunity to participate in typical coursework, has not been available to high school students with intellectual disabilities. The usual options for these students, especially those past the age of 18, have been limited to segregated life skills or community-based transition programs. Inclusive PSE options are beginning to replace such programs and have great potential to improve student outcomes.

The following research findings outline the current knowledge of PSE options and outcomes for students with intellectual disabilities.

- There are approximately 110 PSE programs across 28 states. These programs are listed on www.ThinkCollege.net, a website that is devoted to the topic of PSE for students with intellectual disabilities.
- The majority of programs (74%) support students with disabilities who are dually enrolled in high school and college. Thirty-three percent of the programs supported adult students with intellectual disabilities in PSE. (Some programs support both.)
- Parents and local education agencies initiate the majority of programs.
- Families are expressing an increased desire for their son or daughter with intellectual disabilities to attend PSE after exiting the school system. When surveyed about desired post-school outcomes, 36%

- of parents of students with intellectual disabilities and other low-incidence disabilities indicated that a four-year college was their first choice. Twenty-two percent of parents wanted a community college.
- Families need more information on PSE options to use when developing young adults' transition goals.
 - The majority of postsecondary programs identify "attitude" and "low expectations" as the most significant barriers to overcome. Additional barriers, in order of significance, are funding, including access to student financial aid for students with disabilities who lack a high school diploma; transportation; and entrance requirements, including "ability to benefit" tests.
 - A matched-cohort follow-up study of 40 students with intellectual disabilities looked at 20 students who had some type of PSE experience (noncredit audit, certificate course, courses for credit, fully matriculating) and 20 with no PSE experience. Findings revealed that students with intellectual disabilities who had some type of PSE experience were much more likely to obtain competitive employment, required fewer supports, and earned higher wages. Additionally, students had increased self-esteem and expanded social networks that included students without disabilities, and all involved had overall higher expectations for these students.
 - A survey conducted with 13 programs in one state revealed that 87% of the 163 students in programs in postsecondary sites were involved in employment training, 36% were enrolled in a typical college course, and over half participated in activities on the college campus after school hours. All exiting students were linked to an adult service agency or community rehabilitation program as they exited. Seventy-nine percent qualified for Social Security benefits, 84% had a job for the summer, and 65% exited with a paid job.

Recommendations for Improving Access to Postsecondary Education

The following recommendations for improving access to PSE focus on strengthening three key elements: awareness, policy, and capacity-building.

Awareness

- Develop a multimedia public awareness campaign on the options for and benefits of PSE for students with an intellectual disability. The campaign should reach students and families, school K-12 personnel, adult disability and generic service systems, and the higher education community.
- Encourage state departments of education to identify the current status of PSE options in local districts, monitor student activities and outcomes, and share information about exemplary programs and services in postsecondary environments.

- Inform institutions of higher education and their supporting organizations (e.g., National Council for Accreditation of Teacher Education, National Association for Equal Opportunity in Higher Education, Hispanic Association of Colleges and Universities) of current partnerships serving students with intellectual disabilities. Clearly articulate the institutional and individual benefits of such collaborations.
- Inform national disability organizations (e.g., TASH, AAMR, AUCD/University Centers of Excellence, ARC, UCP, PACER/Parent Training Information Centers, AHEAD) about the options for and benefits of PSE for students with intellectual disabilities.

Policy

- Secure "Dear Colleague" letters from the U.S. Department of Education to state superintendents/commissioners informing them that IDEA funds can be used to support students with disabilities in PSE and develop or enhance options and services.
- Ensure that the State Performance Plans (SPPs) and indicators 13 and 14 required under IDEA include PSE options and track outcomes for students with intellectual disabilities.
- Develop an "alternate" or universally designed "ability to benefit" test that creates access to PSE for students with intellectual disabilities.
- Modify and align existing legislation (e.g., IDEA, HEA, NCLB, WIA, SSA, Transportation Act, DD Act, Medicaid, Olmstead) to support increased access to PSE for students with intellectual disabilities.
- Identify or develop mechanisms for students with intellectual disabilities to access federal financial aid.
- Develop or modify existing policies to support students with intellectual disabilities to gain access to campus housing.

Capacity-Building

- Fund demonstration and research on PSE models to increase the number of available options and develop/disseminate replication materials.
- Partner with a national organization to integrate a focus on PSE for students with intellectual disabilities. This partnership can organize information and resources, provide training and technical assistance, conduct and coordinate research efforts, and advocate for needed legislative and policy changes.
- Develop strategies that support national accreditation for PSE options that integrate students with intellectual disabilities.
- Establish a national set of standards and quality indicators for PSE.
- Integrate information on PSE for students with intellectual disabilities in pre-service training of all general and special education teachers, rehabilitation professionals, and support personnel.

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Web Resources

- www.ThinkCollege.net
- www.transitiontocollege.net

- www.education.umd.edu/oco
- www.transitioncoalition.org
- www.STEPS-Forward.org
- www.heath.gwu.edu

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Studying at the school of life

By Shelley Widhalm
THE WASHINGTON TIMES 2004

Suzan Basoglu, a rising second-year student at George Mason University, has college to thank for coming out of her shell.

"She's more talkative. She's not afraid to approach somebody and talk to them," Fairfax resident Bev Basoglu says about her 19-year-old daughter.

GMU initiated the Learning Into Future Environments program in fall 2002 to prepare Ms. Basoglu and other young adults with significant learning, cognitive or developmental disabilities for employment and independent living.

"We've seen such a change in Suzan," Mrs. Basoglu says. "She reminds us every day that she's not a kid but in college."

Colleges and universities are required under the Americans With Disabilities Act to accommodate students with disabilities as long as they meet the school's entrance requirements. LIFE students do not meet those requirements.

GMU started the program at the urging of parents who wanted to see their children further their educations beyond high school. A survey of area colleges and universities shows that Montgomery College is the only other college with a similar program.

"With our students, it's really easy to focus on all of their challenges and support needs, but you really are ignoring their potential," says Carmen Rioux-Bailey, LIFE program director. "Our program is focusing on abilities. That's what's made our students bloom."

LIFE students earn a certificate after completing the program, typically enrolling between the ages of 18 and 22. They can remain in the program for one to six years, until they are 25. Twelve students participated in the program last year.

"This is an unbelievable program," says Burke resident Michael Toobin, father of Adam, a 21-year-old LIFE student who he feared would not have many options after high school. "We're not on hold with his future. His future is developing with this program."

LIFE aims to help students increase their skills in reading, writing, mathematics and technology, along with independent-living and employability skills. The students learn how to look for and keep a job, and they participate in internships and paid employment.

"It's just so exciting to see the growth of our students," says Clare Talbert, LIFE's program coordinator.

LIFE student Ian Roddick, 20, says the program taught him independence. "I do my own laundry. I do my own cooking. I do my own banking. I do my own stuff without my mom and dad," he says.

LIFE students take career-exploration and independent-living courses through the Graduate School of Education's Helen A. Kellar Institute for Human Disabilities, which houses the campus's disability projects and programs. Courses include Web design, money management, creative arts, and health and fitness. The courses merge functional instruction with academics, so that mathematics, for example, is taught using banking skills and literacy courses include job terminology.

"The way we teach it is geared to using it when they live alone, focusing on academic skills so it's useful for them during the rest of their lives," Ms. Rioux-Bailey says.

GMU students majoring in disciplines such as education, psychology, social work and assistive technology provide the instruction in exchange for tuition support and research stipends. The cost of running the program is covered by LIFE students' tuition, which is \$7,500 per semester, almost triple in-state tuition for undergraduates in the coming school year.

Jamie Bell, a second-year graduate student studying special education, joined the program in spring to gain practical teaching experience. "I get to try out what I learn in class the next day here. That's a very powerful tool," he says.

Mr. Bell watched the students mature, take on more responsibilities and make more decisions. "That's a college type of environment they benefit from, and that feeds their independence," he says.

Other GMU students volunteer as peer mentors to facilitate LIFE students' inclusion in student life and activities, meeting with them at least once a week. The LIFE students and 22 mentors attended school events, went out to lunch and saw campus movies together last year.

[Society spends "a lot of time keeping people out of things," Ms. Rioux-Bailey says. "We would argue, when you think diversity, you need to expand the definition to include people with significant disabilities."

Trevor Wallace, a junior majoring in government, says students with disabilities are like anyone else.

"Just be yourself around them. ... Don't make it seem like their disability will put a block between the relationship," says Mr. Wallace, who mentors the students with fellow members of the Phi Sigma Kappa fraternity. "They want to talk and have fun. There's nothing that can stop them from doing that."

The mentoring program is why 19-year-old Lindsay Beeler, who is majoring in English with a minor in special education, decided not to

transfer to James Madison University.

"They just have shown me a different perspective on things," she says. "It's amazing how outgoing they are. They showed me how much fun you can have."

Eighteen students are enrolled in LIFE for the fall semester. The maximum enrollment is 24 to 25 students, with six new students allowed to enroll each year. Enrollment is open for fall 2005, with a March 1 deadline for applications.

The program staff presented information about LIFE at a special-education conference last year and is mentoring an Illinois college on how to set up a similar program there.

"We would love to see this happen at other places," Mrs. Talbert says.

Montgomery College, which has campuses in Germantown, Rockville and Takoma Park, initiated a Graduate Transition Program last year to help recent high school graduates with developmental disabilities function independently once they complete the program. The two-year certificate program focuses on functional academics and life and vocational skills.

"The students are just thrilled to be finishing the program," says Elizabeth Homan, media relations director for Montgomery College. "They are so excited to say they are going to Montgomery College."

Building Authentic Visions: How to Support the Focus Person in Person Centered Planning

by *Jean Whitney-Thomas and Jaimie Ciulla Timmons*

Introduction

The importance of self-determination for young people with disabilities has become an increasing priority for young people, families, and professionals. Person centered planning has emerged as one mechanism for young people to build self-determined futures with the help of a supportive group of people.

In general, person centered planning encourages an individual to involve personal and community networks in planning for the future. The process includes articulating a vision and coordinating resources and supports to make the vision a reality. Therefore, the effectiveness of planning depends on the support of significant others who assist in problem solving and resource development. Equally important in determining the success of a planning process is considering how facilitators, family members, and other members of the person's social network influence the focus person's participation.

This summary is meant as a resource for facilitators, family members and friends who are invited to be part of a person centered planning process. Recommendations are made to challenge planning team members to think about how their own behavior influences the participation of the focus person.

Methodology

This summary was developed from research conducted at the Institute for Community Inclusion between June 1996 and June 1997. The research examined student participation in Whole Life Planning and involved:

- Ten 18-21 year olds with developmental disabilities in four Massachusetts communities who participated in Whole Life Planning processes.
- These young people were from various cultural backgrounds (Latino (n=3), White (n=6) and Asian-American (n=1)).

The researchers:

- Observed 34 organizational and planning meetings.
- Conducted 17 interviews with the young people, their parents, and facilitators.

Findings

Factors that encouraged participation from the focus person:

- *Speaking directly to or directing questions toward the focus person.* This encourages the student to answer and discourages other participants from answering for them. This can be challenging for families from cultures in which an elder traditionally answers questions. In all situations, negotiate ways in which the focus person's voice can be heard.
- *Verifying* or checking with the focus person on the meaning of his or her answers, responses and suggestions before moving on. Make sure that he or she understands and agrees with the contributions of others. This creates an opportunity to draw the focus person back into the discussion if he or she becomes quiet or withdrawn.
- *Speaking at the focus person's language level.* By rephrasing words or concepts that were abstract, the focus person participates more productively and remain engaged in conversation.
- *Waiting for a response from the focus person.* When the facilitator allows the focus person time to formulate and produce an answer, other family members and friends are less likely to jump in, and the focus person is less likely to rely on them for answers.
- *Using accommodations* to support the focus person's understanding and communication. These include pictures, visual or auditory clues, technology, or any other concrete techniques that facilitate communication.
- *Following the focus person's lead* to change the subject, take a break or talk more about a topic.
- *Setting and maintaining a positive tone.* A positive tone can be maintained by reframing negative comments and addressing concerns in the establishment of action steps after the vision is completed.
- *Setting aside fears and concerns while the vision is developed.* When parents and others feel that their fears and concerns will be addressed during action planning the focus person can be encouraged to speak about their plans for the future and expand upon them during the building of the vision.

Factors that decreased participation:

- *Using jargon.* Words or phrases that were unclear to the focus person.
- *Using the third person.* Speaking about the focus person to the group.
- *Using patronizing language.* Correcting or talking about the focus person in a way that causes the student to lose face or become embarrassed.

Factors that were important for the group process:

- *Writing suggestions* or statements made by group members on flip charts or meeting notes. This provides a visual record of the discussion, increases the amount of shared information, and reinforces group participation.
- *Using good group facilitation skills.* For example: setting and maintaining the group tone, not letting one person dominate, responding to the group as a whole, eliciting input from quiet participants, keeping track of time and taking breaks, and encouraging participants to speak directly to other members of the group.
- *Actively involving the focus person in the group process.* As the group process moves along participation opportunities for the focus person may be lost. Ways to insure the involvement of the focus person in the group process include: Using pictures instead of written notes and teaching the focus person group participation and leadership skills.

Conclusion

When asked to facilitate, organize, or participate in a person centered planning process, it is important to consider how to maximize the leadership of the focus person. The goal of any person centered planning process is to develop a clear vision for the future built on the hopes and dreams of the focus person and to determine the supports and steps necessary to achieve the vision. The role of the group participants is:

- To support and be a resource to the focus person.
- To express their genuine concern and a personal relationship with the focus person.
- To make sure that the plans and visions come from the focus person and reflect what he or she wants from life.
- In order to play these roles well, it is important for each member of a planning group to consider the following:
- Make sure the focus person drives the discussion and planning.
- Leave pre-conceived notions and expectations about the focus person's future at the door.

- Use multiple modes of communication throughout the planning process (written, pictures, objects, etc.).
- Help the focus person learn group process, decision making, and problem solving skills.

Maintaining a balance between one's own participation and the focus person's can be challenging. One set of parents in the study put it beautifully. The father said, "this has to come from Andrew." "I know," said Andrew's mother, "I'm trying so hard to sit on my hands!"

Resources

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Pierpont, J., O'Brien, J., & Forest, M. (1993). *PATH: A workbook for planning positive futures.* Toronto, Ontario, Canada, M6H 2S5)

Smull, M., & Harrison, S.B. (1992). *Supporting people with severe reputations in the community.* Alexandria, VA: NASMRPD. (NASMRPD, 113 Oronoco Street, Alexandria, VA 22314)

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Self-Determination: Is a Rose by Any Other Name Still a Rose?

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We invite you to read this Exchange focusing on the need to have more coherence and consistency in terminology/descriptions and in anticipated outcomes related to self-determination funding. We also invite you to contribute to a national dialogue to seek the coherence and consistency for which the article advocates. You can join the online discussion by visiting the Beach Center website (www.beachcenter.org) and looking on the home page for a link to the discussion board or you may link to the discussion board through TASH.org. Please join in!

Q1

Does self-determination refer to a curriculum that teaches students with disabilities to be self-directed problem solvers, a technique for redirecting funding streams so that adults with disabilities can control the dollars allocated for their supports and services, or a philosophy grounded in democratic values and constitutional principles of autonomy and liberty? Or is it two or even all three of these? And, what terms should professionals use to inform policy leaders, practitioners, self-advocates, and families so that they will advance the self-determination cause?

One of the first times the term “self-determination” was introduced to the special education field, was the 1989 National Conference on Self-Determination sponsored by the National Institute for Disability and Rehabilitative Research. Prior to this conference, a number of researchers began to investigate the effects of choice making and self-directed learning strategies on the performance of students with severe disabilities (see Agran & Martin, 1987; Guess, Benson, & Siegel-Causey, 1985; Mithaug, Martin, & Agran, 1987; Mithaug & Hanawalt, 1978; Ward, 1988). (Note: At that time the terms “self-control” or “self-management” were used.) Shortly after that historic conference, and based on the developing body of research findings on the positive effects of self-management and self-directed learning strategies, the Office of Special Education Programs funded model programs and curriculum-development projects to promote self-determination of youths with disabilities during their secondary education (Ward,

1996; Wehmeyer, Bersani, & Gagne, 2000). Those early programs were well-documented in the literature (Wehmeyer & Sands, 1998) and laid a strong foundation for subsequent research, demonstration projects, and instructional/curriculum models. Although different definitions have emerged through the work of various research teams, the most frequently accepted definition of self-determination in the field of special education relates is: “acting as the primary causal agent in one’s life and making choices and decisions regarding one’s quality of life free from undue external influence or interference” (Wehmeyer, 1996, p. 24).

At roughly the same that self-determination models related to self-direction and problem-solving continued to expand within the field of special education, adults with disabilities began to demand greater control over their lives. Specifically, they sought to have the right to use Medicaid Home and Community-Based Services (HCBS) funds in ways that responded to their choices and needs as they themselves defined those choices and needs. In making these demands, they insisted that HCBS funds to which they are entitled were theirs to direct because they are the entitled beneficiaries – they “own” the funds – and that they, not service provider agencies, should have the right to say how the funds should be used. Moreover, they were displaying their dissatisfaction with living lives controlled by others. Their frontal challenge to the service-provider enterprise is summarized in the TASH newsletter, TASH Connections (March/April, 2005) which includes an excellent overview of policy, practices, and success stories related to this version of self-determination.

The Robert Wood Johnson Foundation funded the first demonstration project on self-determination (the term here refers to self-determination funding) at Monadnock Developmental Services in New Hampshire. This model focused on the development of individual budgets for adults with disabilities that were developed and implemented through the process of person-centered planning (Conroy, Fullerton, Brown, & Garrow, 2002).

This paper focuses on the emerging literature related to self-determination funding which holds that individuals with disabilities should have greater control over the money allocated to serve them than they have had in the past, and that service-provider agencies have now. Our purpose is to review the literature on self-determination funding to analyze terminology/

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descriptions and anticipated outcomes. We have two concerns that have spurred us to write this article. The first is that as students with disabilities who have had a self-determination curriculum as part of their special education curriculum move toward transition to adulthood, they are going to encounter a whole different use of the term (i.e., self-determination) as they consider funding options. Secondly, there are a wide variety of terms regarding self-determination funding that are used interchangeably, and that can unintentionally confuse stakeholders, including individuals with disabilities, families, service providers, and policymakers. For example, some of the different terms used to refer to self-determination funding include self-direction, consumer control, individual budget, and/or individualized funding (and various derivatives of each of these terms and others). In this article we present the broad range of terms/definitions and anticipated outcomes related to self-determination funding; and we invite you to a web-based discussion to express your own perspectives about what you believe the preferred terminology should be.

Table 1 contains our analysis of terminology/descriptions and anticipated outcomes of self-determination funding models as set out in 11 recent (1996–2005) documents (e.g., articles, chapters) about self-determination funding. These are all of the published articles and chapters we were able to locate that specifically address self-determination funding. (Please note that this review relates to self-determination funding, and not the substantial literature that has been published since the 1980s on self-determination related to being self-directed problem solvers.) We included direct quotes of terminology/descriptions and anticipated outcomes where possible. If the terminology/descriptions and anticipated outcomes could not be succinctly encapsulated into a single quote or two, we extracted the major concepts and highlighted those. In some cases, we needed to infer from the author's writing what he or she was intending the outcome to be since this was not explicitly stated. We highlighted key terms in italics and ordered the entries chronologically, starting in 1996 with the Robert Wood Johnson (RWJ) Foundation call for proposals for self-determination projects and continuing through the most recent 2005 publications.

As we read the 11 documents, paying particular attention to terminology/descriptions and anticipated outcomes, it became obvious that no two of these documents define key terms in exactly the same way. For example, Nerney (2005) defines self-determination primarily from a values perspective:

Self-determination for citizens with disabilities is about freedom. *Freedom* to decide how one wants to live his or her life. It's also about organizing needed *support* with the person's support network – friends, family, those who care. Self-determination

means having *authority* over resources and taking *responsibility* for decisions and action. True champions of self-determination honor the important leadership of persons with disabilities in changing our systems of support. *Confirmation* of the self-advocacy movement is a major principle of self-determination. We must not forget whose life is being lived” (p. 3).

Alternatively, Fortune and colleagues (2005) use the term *person-centered system architecture* as contrasted to the term self-determination. Furthermore, they use a functional definition rather than a values definition, but in the following passage they are generally referring to the same thing that Nerney refers to above:

Person-centered system architecture “...(1) attaches funding in the form of an individual budget to each individual; (2) gives individuals, their families, and their allies the authority to select the services and supports that reflect the person's priorities; (3) affirms uninhibited free selection of service providers; and (4) employs open (rather than slot-based) contracting to foster a market place that encourages the free entry of providers” (pp. 241–242).

Comparing and contrasting the actual terms and their descriptions highlights the potential confusion for stakeholders in encountering such discrepant nomenclature. An analysis of the entries in the left-hand column of Table 1 pertaining to terminology/description reveals that the three terms used most frequently are self-determination, individualized funding, and individual budget. Several of the more recent publications (Moseley, 2005; Moseley, Gettings, & Cooper, 2005; Stancliffe & Lakin, 2005) briefly define self-determination or self-direction but then give primary attention to the individual budget.

Our review of the anticipated outcomes (in the right-hand column in Table 1) indicates substantial consistency over time. The anticipated outcome of self-determination/individualized funding/individual budgets primarily relates to individual control (i.e., autonomy). Indeed, five of the publications explicitly identified control as the anticipated outcome. The remaining publications described outcomes in terms of related concepts such as empowerment and decision-making. Thus, there appears to be uniformity with respect to the anticipated outcome of individualized funding/ individual budgets, and that outcome is the autonomy/liberty to control one's own life.

We believe that enhancing consistency and coherence in terminology/descriptions and in the specification of anticipated outcomes is important for a couple of reasons. There is a major need to communicate as clearly as possible about the revolutionary and even transforming potential in policy and practice that redirects how public funds can (and should) be used to

Table 1
Terminology/Descriptions and Anticipated Outcomes

Terminology/Descriptions	Anticipated Outcomes
<p>1. The Robert Wood Johnson Foundation (1996) and Shumway (1999)</p> <ul style="list-style-type: none"> • <i>Self-determination</i> is based on the four principles of freedom, support, authority, and responsibility. • "...the elements of self-determination rests on the ongoing trend toward the following: <ul style="list-style-type: none"> ■ "People with disabilities and their families having a personally controlled, individual budget and the ability to determine how an individual budget will be spent..." ■ "Supports provided in the community..." ■ "Profound changes in public policy that would require new planning, operating, and financing structures..." (Shumway, 1999, p. 31). <p>2. Dowson & Salisbury (1999)</p> <ul style="list-style-type: none"> • "If [<i>individualized funding</i>]...is public funding that is allocated to the individual, based on his/her unique strengths and needs, and placed under the control of the individual to enable them to live in community as a full citizen" (p. 4). 	<ul style="list-style-type: none"> • "Self-determination is an important next step allowing persons and their families and friends, in conjunction with professionals, to be the <i>decision-makers</i> concerning the supports that are needed and how they best can be provided" (Robert Wood Johnson Foundation, 1996, p. 2).
<p>3. Aichroth et al. (2002)</p> <ul style="list-style-type: none"> • "...<i>self-determination</i> has been portrayed as...the value attributed to the autonomy of individuals [which] implies a social responsibility for cultural institutions to ensure that choice and control are available to all, not just some" (p. 17). • "<i>Self-directed services</i> are defined in this way: '...the individual, with appropriate help from the circle of support, will define what is needed, how it is provided, and from whom the service will be purchased...the person receiving support is not the direct employer-of-record' (p. 23). • "In the <i>self-managed mode</i>, the person becomes the employer-of-record for providers...in essence, they manage the money" (p. 23). 	<ul style="list-style-type: none"> • "It [<i>individualized funding</i>] gives people the freedom to develop their lives, using allocated public funds in the way that they consider best. It provides a means to ensure that plans and services will not be imposed upon them by community service providers and public officials. It provides for a process of negotiation between the individual and the holder of public funds. It also obliges service providers to treat the users as value customers and encourages the emergence of innovative services to meet their requirements" (p. 4). • "Such a perspective...allow[s] label people to make their own construction of who they are in the world, and ways in which they seek to have power and <i>control</i> over their lives" (p. 24).
<p>4. Lord & Hutchinson (2003)</p> <ul style="list-style-type: none"> • "...<i>individualized funding</i> refers to the allocation of support dollars directly to the person, in contrast to a service agency" (p. 72). 	<ul style="list-style-type: none"> • "Individualized funding allows people to <i>choose</i> where they will live, how, and who will provide support. Many individualized funding programs promote a wholistic view of quality of life, looking at employment supports, community living, leisure pursuits, and relationship building" (Roehner Institute, 1997, p. 72). • "Individualized funding approaches have substantial benefit for people with disabilities in areas of <i>personal empowerment</i>, cost effectiveness, and reducing dependence on social services" (p. 294).
<p>5. Smith (2003)</p> <ul style="list-style-type: none"> • "<i>Individualized funding and support brokerage</i>, alternatives to more traditional approaches to funding and support planning, are at the foundation of this understanding of <i>self-determination</i> and the cutting edge of the new way of thinking about supports for people with disabilities" (p. 294). 	<ul style="list-style-type: none"> • "...Individuals and families would have greater <i>decision-making authority</i> in the service planning process" (p. 258).
<p>6. Fortune et al. (2005)</p> <ul style="list-style-type: none"> • <i>Person-centered system architecture</i> "...(1) attaches funding in the form of an individual budget to each individual; (2) gives individuals, their families, and their allies the authority to select the services and supports that reflect the person's priorities; (3) affirms uninhibited free selection of service providers; and (4) employs open (rather than slot-based) contracting to foster a market place that encourages the free entry of providers" (pp. 241–242). 	

Table 1
Continued

Terminology/Descriptions	Anticipated Outcomes
<p>7. Head & Conroy (2005)</p> <ul style="list-style-type: none"> • “Each participant was first engaged in a <i>person-centered planning process</i>... the plan was transposed into an <i>individual budget</i>...The plan and the budget were then compiled in a written <i>self-determination agreement</i>... [which] authorized the person to proceed to select, control, and direct a provider arrangement necessary to accomplish the plan” (p. 221). 	<ul style="list-style-type: none"> • “The <i>control</i> gained by individuals involved three main aspects of life. First, some individuals moved from settings that were licensed and regulated to supported independence. Second, individuals were supported and allowed to incorporate more allies into their lives. Allies were freely selected family members and friends. Third, with the support of these allies, individuals were expected to make decisions about the facets of their lives that mattered most to them. These included their jobs and other day activities, as well as other major aspects of how public funds were used” (Head & Conroy, 2005, p. 235).
<p>8. Moseley, Gettings, & Cooper (2005)</p> <ul style="list-style-type: none"> • “<i>Self-determination/consumer-direction/self-direction</i> – Belief based on the understanding that people have both the right and responsibility to exercise control over the services they receive. This belief is also based on four related principles of freedom, authority, support, and responsibility (Shumway, 1999)” (p. 265). • “<i>Individual budget</i> – A mechanism establishing an amount of funding available for an individual with disabilities to direct and manage the delivery of services he or she is authorized to receive” (p. 266). 	<ul style="list-style-type: none"> • “...<i>empower</i> individuals with disabilities to take charge of the supports they receive...” (p. 284) • “...<i>force</i> traditional systems of service delivery to change – to increase their responsiveness to consumer needs, preferences, and desires for individual <i>control</i>” (p. 284).
<p>9. Stancliffe & Lakin (2005)</p> <ul style="list-style-type: none"> • “...<i>initiatives that promote self-determination</i>...[include] having an <i>individual budget</i>, exercising control over services and decision-making, using person-centered planning, having independent support brokerage, and having a fiscal intermediary (Moseley, 2001...)” (p. 203). 	<ul style="list-style-type: none"> • “...reduction in staff control of service recipients’ lives and greater self-determination, especially regarding <i>control</i> over one’s services...” (p. 204).
<p>10. Nerney (2005)</p> <ul style="list-style-type: none"> • “Self-determination for citizens with disabilities is about freedom. <i>Freedom</i> to decide how one wants to live his or her life. It’s also about organizing needed <i>support</i> with the person’s support network – friends, family, those who care. Self-determination means having <i>authority</i> over resources and taking <i>responsibility</i> for decisions and action. True champions of self-determination honor the important leadership of persons with disabilities in changing our systems of support. <i>Confirmation</i> of the self-advocacy movement is a major principle of self-determination. We must not forget whose life is being lived” (p. 3). • “<i>Individual budget</i> was defined as the amount of funding made available to a person with developmental disabilities to enable him or her to manage and control the services she or he is authorized to receive” (p. 166). 	<ul style="list-style-type: none"> • “The purpose of self-determination is to make it possible for individuals to craft personally meaningful lives in our communities. Principles of self-determination establish that individuals with disabilities are the <i>planners</i> and <i>decision-makers</i> in how they spend their day and in how they live their lives, with caring assistance available when needed” (p. 3).
<p>11. Moseley (2005)</p> <ul style="list-style-type: none"> • “<i>Self-direction</i> or <i>self-determination</i>, the term used in many states to refer to <i>self-directed services</i>, is not a service model but rather an approach to structuring the way supports are offered. States must make several program-related structural, financial and functional changes to implement self-directed services” (p. 166). 	<ul style="list-style-type: none"> • “Three significant outcomes accompany the implementation of self-directed services. First, the shift of financial authority <i>empowers</i> individuals receiving support to act as true consumers with the ability to purchase services from the provider(s) of their choice. Second, self-directed systems of service delivery strengthen the relationship between the state as the funding entity and the persons receiving support as consumers. Third, the scope of provider agency involvement becomes <i>set by the individual</i> who has responsibility for determining the role the service provider will play in his or her life” (p. 166).

enhance individual control. The best case can be made in advocating for policy, developing model programs, and preparing youth with disabilities and their families for this type of adult support if there is a common nomenclature. It is noteworthy that the two lines of

work on self-determination – the education and the fiscal-control lines – have been carried out in a parallel fashion over the last decade, but that only two articles to date have sought to merge best practices from both lines of work (Turnbull & Turnbull, 2000; Turnbull &

Turnbull, 2001). We believe that there is mutual benefit for both lines of research on self-determination to incorporate key findings from the other line. For example, demonstration projects that are redirecting public funds to individuals with disabilities can benefit from incorporating the knowledge and skill development processes that have been documented as evidence-based practices in enhancing self-directed problem-solving. Alternatively, a way to enhance the utility and potential quality of life outcomes of self-determination skills training at the secondary level would be to prepare students (and their families) in knowledge and skill related to accessing, implementing, and monitoring individual budgets.

Terminology related to self-determination funding needs to be considered in light of the terminology to which many children and youth with disabilities and their families are introduced throughout their elementary and secondary special education program. Terminology in the lexicon of adult services should be consistent with terminology in the lexicon of schools, because the words and phrases create expectations for curriculum, behaviors (by professionals, individuals/students, and others, including their families), and outcomes (for individuals and for service systems).

We encourage you to contribute to a national dialogue to increase the coherence and consistency in terminology/descriptions and anticipated outcomes related to self-determination funding; we will work towards terms that are clear, succinct, and reflective of the values that underlie them. The Beach Center, in collaboration with AAMR and The Arc-U.S., is hosting a discussion in an online format over the next several months on the following questions:

- What are the defining characteristics of self-determination funding?
- What are the preferred outcomes of self-determination funding?
- What is the preferred terminology for self-determination funding?

To join the online discussion, please visit the Beach Center website (www.beachcenter.org), and look on the home page for the link to the discussion board, or you may link to this site through the TASH website (www.TASH.org). We will archive the results and have them available both on the Beach Center and TASH websites.

In closing we ask: Is self-determination by any other name still self-determination?

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Q2

Q3

Q4

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AUTHOR QUERIES

AUTHOR PLEASE ANSWER ALL QUERIES

Q1 = Please provide keywords.

Q2 = For the Conroy et al., 2002, bibliographic entry, please provide the authors' initials and publication data.

Q3 = Please provide publication data for Roehrer Institute, 1997, which appeared in Table 1, and include the entry in the bibliographic list.

Q4 = For the Nerney, 2005, bibliographic entry, please provide the volume number of the newsletter and the pages in which the article appeared.

END OF AUTHOR QUERIES



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Making Dreams a Reality: Using Personal Networks to Achieve Goals as You Prepare to Leave High School

by Jaimie Ciulla Timmons, Mairead Moloney, Danielle Dreilinger, and Jennifer Schurter

Introduction

Getting ready to leave high school can be both exciting and stressful. Young adults with disabilities need to figure out what their interests are and develop goals for the future. Decisions need to be made about where the young adult might live, what kind of job they might have, or where they may continue their education. New life options create opportunities for more decision-making. Although young adults with disabilities may become more independent during this time, the support and encouragement of others remains crucial for success.

The Institute for Community Inclusion (ICI) interviewed high school students with disabilities and their parents/guardians. ICI asked these families about their plans for the future and how others may have influenced their decisions. In addition, both students and their parents were asked to tell ICI about important decisions they have made as a family, and who they depend on when there is a problem and support may be needed.

Three stories

Many of the students and parents who participated in ICI's study described how they used and depended upon their **personal networks**—both formal and informal—to figure out what they need and want, and help them discover, reach for, and achieve their personal goals. In addition, these personal networks helped to develop **self-determination** in the young adult. The three stories that follow illustrate ways that students used personal networks to help them achieve their goals, and sometimes, how they could be better used to make their goals a reality. These examples also illustrate how **personal network members** helped to develop self-determination.

(The stories that follow are based on conversations with the students and their parents. Please note that names have been changed to protect their privacy.)

What is self-determination?

People who have self-determination know what they want and how to get it. They know a lot about themselves and have a clear vision for the future. Self-determined people can make decisions for themselves, and know what they have to do to achieve their goals. They feel independent and in control of their life plans. A self-determined person does not need to know all the answers, but they know that there are a variety of options in life that are available for them. They understand their own strengths and weaknesses, try to solve problems, and make their own choices. Self-determination is related to self-esteem and confidence because in order to pursue your goals, you need to feel that you can do it! In addition, self-determined people know how to find help when they need it. This help usually comes from their **personal network**.



What is a personal network?

A personal network is basically everyone that a person knows. This includes both **formal** and **informal** network members. Formal network members are professionals such as school counselors or teachers. Informal network members are people close to you, like your friends, family members, and others you may have met in social organizations, sports teams, religious organizations, or even in your neighborhood.

How can a personal network help to develop self-determination?

Personal networks can guide the self-determined person as they solve problems and support them when important decisions are made. People from the personal network help teach new skills as goals are achieved. The self-determined person learns to plan and coordinate their lives with help from these important people. Members from the personal network provide more and more opportunities for the self-determined individual to make decisions and learn new skills on their own.

Story 1:

I found what I needed to move forward.

Heather, a recent high school graduate with physical and special health care needs, expected to have a full-time job, live with her boyfriend, and someday have kids of her own. She felt very strongly about the value of work, as she said, "I want to work 100%. I want to work for my money." Heather's mother, however, was concerned that a full-time job would have a negative effect on Heather's Social Security benefits.

Despite her mother's concerns, Heather was determined to go forward. Throughout high

school, Heather's personal network exposed her to a variety of employment opportunities. When she was looking for a summer job, a family friend who worked in landscaping helped her find a job in the business. In addition, her brother introduced her to the auto body field by letting her work on his car. This led Heather to take classes in auto body at school to gain more experience. These experiences gave Heather the knowledge to develop work and career goals. Heather gathered the support she needed from her boyfriend and brother who went with her as she collected job applications, helped her fill them out, and provided encouragement. Heather's brother advocated on her behalf to their mother. "He's the one that's fighting with my mother telling her that I should work." Heather also applied for jobs independently and used school personnel to help her uncover the Department of Vocational Rehabilitation (VR) as an additional resource. She set up an appointment with a VR counselor on her own. All these activities led her to find a job in a field that matched her interests.

Important points:

- ▶ Heather's network gives her opportunities to discover her preferences by exposing her to a variety of work experiences.
- ▶ Heather chooses to work. Her self-determination is evident in her strong desire to work despite her mother's concern.
- ▶ Heather demonstrates self-determination not only by independently finding VR as a resource, but by gathering support from her boyfriend and brother.
- ▶ Heather makes substitutions for gaps in her personal network. Because she feels her mother was not supportive, she finds other people (her brother, boyfriend, and school personnel) to help her out. Positive network members balance out other members who have reservations.
- ▶ Heather uses a combination of informal network members (brother and boyfriend) as well as formal network members (school personnel, counselor from VR) to reach her employment goals.
- ▶ Heather's informal network provided both encouragement and specific help (like filling out applications).

Story 2:

Shared goals and a champion's support bring success

Shantelle, a recent high school graduate with a psychiatric disability, worked part-time while living at home. A large, dependable network of both formal and informal network members helped support her as she developed her goals. This

included a close friend, teachers, a therapist, and a neighbor who employed her as a babysitter. Shantelle talked to a close friend and teachers about her decisions for a career, and a therapist about more personal problems.

Most importantly, Shantelle has had great support from her mother. They agreed in their hopes and goals for her future. Shantelle said her mother supported her to reach greater independence: "She doesn't suggest anything. She thinks it should be my concern and my issues what I should do. She thinks I am responsible for myself. She lets me make my own decisions... [but] if I don't know if it's a good or bad idea I ask for her opinion." Shantelle's mother confirmed this by saying "if she says she wants to try something I don't stop her.... We let her make her own decisions. The only way you are going to learn is to make the mistake on your own."

The only challenge Shantelle's mother saw that could stand in Shantelle's way was her tendency towards low self-esteem. This motivated her to surround Shantelle with support. Shantelle's mother gained insight through talking to teachers, the family doctor, church members, and even neighbors. "That's what it takes, you know. Keeping that self esteem up and saying... 'We know you can do it.'" Shantelle's family and friends were quite proud of her. Shantelle's mother best summed up her philosophy and optimistic outlook for her daughter when she said, "We're all looking for a bright future for her."

Important points:

- ▶ Shantelle's mother supports Shantelle's self-determination by listening and making suggestions, and not making decisions for her. Shantelle's family and friends focus on building her self-esteem and confidence so she can move forward and be more self-determined.
- ▶ Shantelle has a large personal network that includes both informal network members (close friend, neighbor, and especially a strong relationship with her mother) and formal network members (teacher and therapist).
- ▶ Shantelle uses members from her personal network differently—some she talks to specifically about work (friends and teachers), while others support her more personal concerns (therapist).
- ▶ Shantelle's mother uses her own network to learn how to support Shantelle and encourage self-determination.
- ▶ Shantelle's mother makes sure not only that **she** is surrounded by support, but uses her own network as an expansion of support for her daughter.
- ▶ Shantelle and her mother are in **alignment**. This means that they agree, and share high expectations for the future. This alignment and shared goals are crucial in maximizing Shantelle's self-determination.

More about where this came from

These stories are based on interviews with high school students and their parents/guardians. Each student and their parent/guardian were interviewed for roughly 45 minutes. Nine students and eight parent/guardians (6 mothers, 1 father, and 1 foster mother) were interviewed in total.

The families who participated in this study were probably much like your own. They had varying racial/ethnic backgrounds, and the students ranged from freshmen to seniors in high school. The young adults had a wide range of disabilities including physical, cognitive, learning, emotional/psychiatric, behavioral, and sensory impairments. Some families lived in suburban locations while others lived in cities.

Story 3:

On the road to self-determination

Carlos, a recent high school graduate with a cognitive disability, had a variety of interests including art and electronics and was very serious about working. However, while he had

ideas about careers that would fulfill his interests, he did not know how to make it happen. He had high expectations for his future and didn't want to settle for any old job. High school frustrated him because he felt that the work experiences and skills he learned there would not prepare him for the working world: "I am not going to get anywhere with those jobs." Although he advocated to change his situation at IEP meetings, school personnel did not change his program.

Carlos' mother was also disappointed by his school, and supported his advocacy efforts. However, she was concerned that Carlos's standards might be too high. "He doesn't want to take any suggestions.... I don't think he understands [that] he doesn't get to pick and choose." She also doubted whether he would be able to pursue the jobs he liked. "It's kind of, like, out of his grasp, but I don't say that."

Carlos and his mother used two formal network members to help him succeed. This included a professional from a private organization and a counselor from the Department of Mental Retardation (DMR). Carlos's mother coordinated these services. Carlos' mother also used his monthly SSI check as a "bank account" to give him experience in using money. However, Carlos's mother reported that they didn't use their own personal network as a resource: "We're it, my husband and I." One result is that, according to Carlos's mother, Carlos relied on her too much.

While Carlos's mother wanted Carlos to be independent, she feared that he would make bad choices if left to his own resources. "I don't think he is mature enough to understand what the big decisions are and how he can handle them." She didn't know how to support him to make good decisions on his own without her making them for

him. "I kind of guide him.... I kind of sway him, kind of try to con him into it."

Carlos felt the lack of support. Despite a college course in computers, he didn't feel confident that he could find a job he liked. Carlos felt stuck. "I don't want to be alone... for the rest of my life. And I don't have a good job that I am good at."

Important points:

- ▶ Carlos demonstrates self-determination through his strong desire to work, not settling for the limited options offered him by his school program, and self-advocating at school IEP meetings.
- ▶ Carlos shows self-awareness in that he had clear interests. Having self-awareness is a crucial first step to being self-determined.
- ▶ Carlos's family helps to develop self-determination by encouraging him access to his SSI checks. Carlos's mother uses SSI as a tool to increase independence, learn the value of money, and teach financial planning. However, Carlos's mother is responsible for coordinating the support from his formal network rather than Carlos doing it himself.
- ▶ Carlos and his family use formal network members to help him reach his goals. However, Carlos and his mother may not know how useful informal network members such as friends and family could be. A broader range of informal contacts could give Carlos a fuller array of assistance and help him get a clearer focus on his goals, skills, and opportunities.
- ▶ There is a **lack of alignment** between Carlos and his mother. This means they did not agree or share the same expectations for Carlos's future. Although they shared the vision that he would work and live independently in the future, they disagreed about what jobs he is capable of pursuing at that stage. Carlos's mother thought that Carlos was too picky. Carlos, on the other hand, didn't want to waste his time on jobs that didn't match his interests.
- ▶ Carlos feels **powerless**, like he was not "in the driver's seat." This is the opposite of self-determination. Carlos does not see himself as being on a positive path to a fulfilling future.

What can Carlos & his family do?

Carlos's mother can begin to give Carlos more responsibility in coordinating the support he receives from formal network members. In addition, while continuing to rely on their formal network members, Carlos and his family could develop their informal network. In this way, Carlos could gain a fuller array of assistance, particularly in areas that he is interested in, with the addition of the personal knowledge and insight that family, friends, and neighbors can give. Their support could help Carlos get a clearer focus on his goals, skills, and opportunities. How can a family develop their personal network? It may not be as hard as you think!

Here is what you and your family can do...

You and your family can identify and expand your personal networks and think about ways to reach out to them and practice self-determination.

Map out your current personal network

- ▶▶ Use the diagram on the top of **Worksheet #1** to make a list of everyone you know. This should include all people that you know well enough to have a conversation with. Include family members, friends, community members such as neighbors, and professionals such as teachers, counselors, employers, and co-workers.

Build your personal network:

- ▶▶ Go on a few informational interviews. The goal of this type of interview is to learn about a type of job or a certain company, not to get a job. Informational interviews are an excellent way to explore different interests and jobs while making new contacts. People in your network can help you set up interviews where they work.
- ▶▶ Join different community groups such as local neighborhood organizations, clubs, religious organizations, or recreational facilities.
- ▶▶ Volunteer for a cause you believe in, or an activity that interests you.

- ▶▶ Participate in community events, such as those sponsored by local groups, schools, and libraries.
- ▶▶ Focus on developing relationships. Establish trust. Spend time doing this before you make specific requests of people.
- ▶▶ Think about ways that you can help your network members. Offer your help. Remember, you can be helpful to your network members just as they are helpful to you.

Reach out to your network:

- ▶▶ Ask for help when you are facing big decisions in your life.
- ▶▶ Take the time to tell people what you are thinking about, share your goals, and the challenges you may be encountering.
- ▶▶ Be specific about the ways that you would like people to help you.
- ▶▶ Ask people in your current network about career ideas, and explain your interests. Network members may know about employment opportunities or be helpful in exploring job ideas with you.
- ▶▶ Ask people in your network to introduce you, or refer you, to people they know who may be helpful to you. This can lead to new opportunities.
- ▶▶ Don't be afraid to ask more than once.
- ▶▶ Realize that members in your network will play different roles and you will not get the same thing from each member.
- ▶▶ Realize that network members aren't always able to help. There may be times when you ask for help and they are not able to give it to you. This is okay!
- ▶▶ Keep your network updated on your progress. People like to help and it will make them feel good to know that you are working toward your goals.

You are already exercising self-determination just by reaching out to those you know. Remember, a **self-determined person knows what they want and can find the support to achieve their goals!** It's up to you to find this support.

A good network member:

- ▶▶ Thinks of themselves as a resource.
- ▶▶ Is willing to listen. He/she may offer suggestions or different ways to think about your decision or issue.
- ▶▶ Will make time in their schedule for you.
- ▶▶ Offers encouragement, guidance, and advice when you need it.
- ▶▶ Is a positive role model.
- ▶▶ Should never be someone you feel uncomfortable with or someone who puts you down.
- ▶▶ Is someone you can trust.
- ▶▶ Is someone who is happy to share his/her experience with you.

A good network member **supports self-determination** by:

- ▶▶ Asking questions but not directing or making decisions.
- ▶▶ Allowing you to experiment with more responsibility, encouraging you to be more responsible for yourself.
- ▶▶ Allowing you to make mistakes in order to learn from them.
- ▶▶ Offering fewer suggestions to encourage independent decision-making.
- ▶▶ Letting you know that they think you are capable and support the decisions you make independently.
- ▶▶ Building your ability to gradually handle your own affairs.
- ▶▶ Boosting your self-confidence.

Ideas for building independence and self-determination

- **Schedule** an informational interview in an area of interest. **Plan** and rehearse phone calls and interviews with someone in your network.
- **Take responsibility** for setting up job interviews and doing job searches. **Participate** actively in all aspects of your job search.
- **Get involved** in school meetings. Bring a list of questions and concerns to your IEP meeting. Consider conducting your own IEP meeting with guidance and support from your school personnel. Remember, they are there to help!
- **Learn** responsibility through household chores, cooking meals, or having a pet. **Hard work often produces rewards!**
- **Experiment** with public transportation when you don't have to be anywhere important. This is a good way to be able to eventually get to a job or friend's house without having to rely on others.
- **Practice** opening and managing a checking or savings account. Having a savings account is a good way to begin saving money for college, a first car, or moving out on your own.
- **Share** in family bill-paying. This helps to understand the value of groceries, clothing, personal items, or rent.

Figuring out what you want:

The **first step** to self-determination

Start by figuring out what you want for yourself. These should be your dreams, not someone else's dreams for you. Explore different career options. Think about what you are good at and what makes you happy. Use the bottom of **Worksheet #1** to think about who you are and create a personal vision statement. Write this statement down on paper. Remember, a self-determined person understands his/her own strengths and weaknesses, and knows a lot about themselves. Self-determined people may not necessarily know exactly what they want at all times, and their visions may change from one day to the next, but they know how to get what they need.

Going out and getting it:

The **second step** to self-determination

Once you have figured out what you want, it is time to develop clear goals and come up with an action plan. Use **Worksheet #2** to think about where you would like to see yourself down the road. Again, write down your plan step by step. Take out your list of network members and think about how each member might be able to help. Put a star next to the names of those that you feel especially close to, and whom you would be comfortable asking for help. Different people in your network can probably help you in different ways. Be willing to ask for help and be specific. Remember, you don't need to have all the answers. **Self-determined people know how to get what they want and know how to find help when they need it. They can define their goals and take initiative in achieving them.**

Starting early

Although the students in these stories are recent high school graduates, you and your family should not wait until then to start building these skills. In fact, it is important to build these skills early in high school. The point is... it is never too early to start practicing self-determination and expanding your network! So get started!

Conclusion

Being self-determined is exciting, although making your own choices can be difficult sometimes. Don't be afraid to find and ask for help. Reach out to your personal network and ask them to help you reach your goals. Don't get discouraged if you feel like you don't know what you want, you change your mind, or you've made bad choices in the past. It's okay to make mistakes. **Remember you are capable and you can do it!**

Additional ICI resources on this topic

Tools for Inclusion Series

www.communityinclusion.org/publications/tools.html

Stories of Success: Using networking and mentoring relationships in career planning for students with disabilities.

(February 2001, Vol. 9, No. 1)

Networking: A consumer guide to an effective job search.

(January 1999, Vol. 7, No.1)

Training Manuals

Building a Self-Determined Future For All Youth. (2001)

This manual offers an exciting approach to teaching and learning leadership and self-determination skills. It is divided into twelve curriculum units that are designed to introduce middle and high school students to a broad spectrum of leadership and self-determination skills. The guide is interactive and contains a collection of learning activities and materials that pertain to leadership.

Building Community Connections: Designing a Future That Works. (1996)

This manual serves as a curriculum for a two-day workshop designed to teach individuals with disabilities to utilize their contacts in a job search. Topics covered include: tapping the hidden job market, using networks for career development and job searches, identifying and engaging individuals, keeping in touch with people without becoming a pest, creating a mutually beneficial relationship with potential employers, dealing with disclosure, and using service providers.

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This publication will be made available in alternate formats upon request.

Mapping your personal network

Family

Friends

Community members (neighbors, people from clubs or groups)

Professionals (school personnel, counselors, people from jobs)

Who am I and what do I want? Solving the puzzle

Who am I?

Subjects I like(d) in school are:

Activities (sports, clubs, volunteer work) that I like are:

Things I like to do in my free time (work, spend time with friends, etc.) are:

My strengths are:

My weaknesses are:

What is my dream?

What types of goals do I have for myself?

What would be my ideal job? Why?

What is important for me to be happy?

How do I envision my life after high school? In 5 years? In 10 years? When I'm my parent's age?

My goals and dreams for the future are:

Worksheet #1

Going out and getting it! Planning for the future

When filling out this worksheet, think about your goals in four specific areas of your life. These are: work, learning, living situation, and leisure/recreation. Separate each area, and write out goals and steps for each.

Getting it down on paper

Something I would like to accomplish this year is:

I will take the following steps to achieve this:

Step one:

Step two:

Step three:

My goals for when I graduate are:

I will take the following steps to achieve these goals:

Step one:

Step two:

Step three:

My goals for when I'm my parent's age are:

I will take the following steps to achieve these goals:

Step one:

Step two:

Step three:

Just do it!

What types of decisions do I have to make?

What problems may come up and how do I solve them?

Some decisions I made this week are:

Gathering support

When I have had problems in the past, who has helped me solve them?

Who can help me achieve my goals? And how might they help?

Person *1 _____ How they might help _____

Person *2 _____ How they might help _____

Person *3 _____ How they might help _____

Person *4 _____ How they might help _____