

Collaborative Community Transition Planning Process
Report to the Community
December 14, 2006

In the Balance: Successfully Transitioning to a Meaningful Adult Life



The Struggle of Self-Determination for Students with Developmental Disabilities

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Table of Contents

I.	Introduction	Page 1
II.	Executive Summary	Page 3
III.	Developmental Disabilities and Transition Services	Page 7
IV.	What Ideally Happens as a Student with Developmental Disabilities “Transitions” from the World of Education to the Adult World?	Page 11
V.	How Information was Gathered and Reviewed	Page 13
VI.	What We Learned	Page 14
	A. The Experience of Students with Developmental Disabilities	Page 14
	B. The Experience of Families Who are Supporting and Advocating for Students with Developmental Disabilities	Page 17
	C. The Experience of Educators	Page 21
	D. The Experience of Adult Services Providers	Page 26
	E. The Experience of City of Rochester Experts	Page 32
VII.	Major Findings	Page 35
VIII.	Recommendations	Page 37
IX.	Steps Forward: Outcomes So Far	Page 49
X.	Next Steps	Page 50
XI.	Conclusion	Page 51
XII.	Appendices	Page 52

I. Introduction

In April of 2006, over one hundred members of the Greater Rochester, New York community—youth with developmental disabilities and supportive family members, educators, administrators, advocates, community leaders, state agency and adult services personnel—gathered to begin a comprehensive examination of the transition process from high school to the adult world for students with developmental disabilities. Since then we have convened Expert Panels, reviewed data, explored best practices and held many discussions to provide us with further information and insights on transition.

The data we gathered in this process is largely qualitative and relies on people's perceptions of their experiences. Strong themes emerged in the discussions by the Expert Panels. Quantitative data in the field supports the qualitative data and illustrates that outcomes for students with developmental disabilities are less positive than outcomes for students without disabilities.¹ For example:

- Of the students with disabilities who plan to work after high school, only 57% secure a job within one year of leaving school, compared to 82% of general education students who plan to work after high school.²
- One year after graduation, 26% of students with mental retardation have no active program (including employment, day program alternatives, post-secondary education, and other), compared to only 4% of general education students.³

Students with disabilities are not realizing their hopes and dreams. For example:

- Fewer students with disabilities went on to college than were expecting to. About 77 percent of students interviewed while in high school said they aspired to get a postsecondary education, but only 31 percent had taken some postsecondary classes in the period after they finished.⁴

National and statewide data and the local voices of individuals, families, and professionals tell us that students with developmental disabilities are struggling through the transition process and not realizing their hopes and dreams. The gaps in experiences and outcomes between students with developmental disabilities and students without disabilities demand our attention.

¹ The data available to us compares outcomes for students with disabilities to outcomes for students without disabilities. We are not aware of data that specifically compares outcomes for students with developmental disabilities to students without disabilities. Some studies break down outcomes according to specific disabilities or educational classifications. However, there is no clear correlation between those disability classifications and the developmental disability criteria used in New York State.

² NYSED Longitudinal PSI Study, January 21, 2003, New York State Education Department, Office of Vocational and Educational Services for Individuals with Disabilities, April 2003

³ New York State Part B Annual Performance Report 2003-2004, New York State Education Department, Office of Vocational and Educational Services for Individuals with Disabilities

⁴ After High School: A First Look at the Postschool Experiences of Youth with Disabilities, US Department of Education, 2005

In all our work, we are guided by our belief that individuals with developmental disabilities are entitled to the support they need to achieve independence, choice and the ability to pursue their own hopes and dreams.

As members of the Steering Committee of the Collaborative Community Transition Planning Process, we are pleased to provide this report, which chronicles what we have learned. We ask every reader to join with us in implementing the recommendations detailed in the report and keeping our collaborative efforts moving forward.

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II. Executive Summary

In this report, students with developmental disabilities speak for themselves, as do parents, teachers, advocates, administrators, and adult services providers. All these groups are partners in assisting students as they “transition” from the world of secondary education to an adult world in which hopes and dreams can be pursued. Remarkably, when put together, all these different voices present a united chorus on the problems facing transition planning.

The major findings of the Collaborative Community Transition Planning Process are:

- A. There are two very different worlds involved in transition: the world where students with developmental disabilities are “entitled” to an education that meets their needs, and the world where adults with developmental disabilities may be “eligible” for programs and services. These worlds know too little about each other, use different vocabulary, have different cultures and are connected in a haphazard way. Each world will significantly benefit from increased training, support and collaboration with each other. Students with developmental disabilities and their families must have the skills, knowledge and support necessary to be able to succeed in both worlds.
- B. While federal and state laws and regulations are in place to support successful transition, they are not consistently enforced or implemented.
- C. Extensive research has been conducted to determine transition practices that make a difference for students. These practices include⁵:
 - 1. Student participation in the planning process
 - 2. Parents as active and informed partners
 - 3. Transition planning early in the secondary school years
 - 4. Quality vocational training
 - 5. Meaningful community based work experiences
 - 6. Effective, systemic and sustained interagency collaboration

Implementation of these practices remains extremely challenging.

- D. Parents are poorly informed about transition, school district procedures, and choices available to their children after leaving high school. Parents, teachers and providers are often unaware of outstanding resources - highly competent, caring

⁵ See, for example, *The Transition Experiences of Young People with Disabilities: A Summary of Findings from the National Longitudinal Transition Study of Special Education Students*. M. Wagner, J. Blackorby, R. Cameto, K. Hebbeler, and L. Newman. Menlo Park, CA: SRI International, 1993; DeFur, Sharon, *Designing Individual Education Program Transition Plans*. Eric Digest #E598, 2000; Mueller, Roberta, *Missed Opportunities: The State of Transition Services for Youth with Disabilities in New York City*. New York, N.Y. New York Lawyers for the Public Interest, Inc., 2005. West, L., Corbey, S., Boyer-Stephens, A., Jones, B., Miller, R. & Sarkees-Wircenski, M., *Integrating Transition Planning Into the IEP Process*. (2nd ed.) Reston, VA: The Council for Exceptional Children, 1999.

professionals and well designed materials - available to assist them. Cultural differences further hamper communication efforts.

- E. Too few choices are available to students as they move from the world of education to the world of work or higher education; those choices that are available must largely fit into a traditional mold. Limited funding models make even the most creative choices difficult to achieve. School and agency personnel too often focus on fitting students into an existing adult program rather than listening to the student's interests, skills, hopes and dreams.
- F. The quality of services provided to students and their families varies widely from school district to school district and even within school districts.
- G. Planning for the needs of students aging out of mandated educational services is woefully inadequate. The number of students with developmental disabilities leaving school districts each year is unknown. Information is not readily available on their needs.
- H. Without a "Champion," an advocate working with the student, the chances for achieving a successful transition are enormously reduced. The state agencies charged with overseeing transition systems are complicated, not coordinated with each other, and often work at cross-purposes. In the face of such bureaucracies, even the most assertive, educated and responsible parents struggle.

Each of these findings merits intense scrutiny and the development and implementation of recommendations designed to address them. The Steering Committee has begun with several concrete, "doable" recommendations, which we believe can be implemented primarily by collaborative efforts of people already engaged in providing transition services and by seeking grant funds to underwrite pilot programs.

Priority Recommendations⁶

1. Improve overall communications between school districts, adult services providers and families with specific activities. For example:
 - Implement a pilot project to demonstrate effective planning and sharing of information between school districts, Office of Mental Retardation and Developmental Disabilities (OMRDD) and adult providers
 - Develop a common application to be used for adult services programs
2. Provide training for school district staff, families and adult services personnel. For example:
 - Create a pilot training program for transition "champions"
 - Increase dissemination of informational resources already available

⁶ The comprehensive list of all the recommendations developed by the Steering Committee can be found on Page 38.

- Develop “Key Questions” list and check lists to assist families in planning and implementing transition efforts
3. Advocate for systemic changes. For example:
- Enhance curriculum at local colleges to better prepare future educators
 - Advocate for more flexibility to allow community-based experiences as part of students’ school programs
 - Standardize definitions and terminology used by schools and adult service providers
 - Conduct outreach to area colleges and universities to facilitate post-secondary opportunities for students with developmental disabilities

Steps Forward: Outcomes So Far

The Collaborative Community Transition Planning Process initiated a dialogue that needs to continue. In just over six months of work, we have seen:

- Increased linkages and collaboration between a variety of stakeholders involved in transition
- Increased understanding of the barriers to successful transition
- Efforts by the Finger Lakes Developmental Disabilities Service Office (DDSO) to gather more comprehensive, detailed information on students who recently aged out of the educational system
- Increased discussion within and between school districts regarding the collection of data on transitioning students for planning purposes
- The development of comprehensive recommendations for improving the process which are presented in this report

Next Steps

This report is not a final product of the Collaborative Community Transition Planning Process, but rather an update to the community. The Steering Committee plans to continue seeking input, developing recommendations and supporting their implementation. We hope each reader will add his or her voice to all these efforts. Working together, we can empower students with developmental disabilities to pursue their hopes and dreams.

The Steering Committee will continue its work in 2007 and invites interested people to:

- Assist in the implementation of recommendations detailed in this report
- Develop pilot project proposals that further the work and recommendations of this project
- Guide and monitor efforts to implement recommendations
- Develop and support the implementation of new recommendations

Anyone interested in working with the Collaborative Community Transition Planning Process should contact Allyn Stelljes-Young at stelljes-young@advocacycenter.com.

Conclusion

Throughout this report, we are reminded that students with developmental disabilities want, need and deserve the same opportunities to plan their futures as other students. The laws, systems, practices, personnel and resources support this happening, but much more needs to be done to successfully integrate all the parts involved in transition planning. More creative options are needed to respond to the hopes and dreams of our students.

Let the voices of our youth continue to bring us together and motivate us as we take on these challenges.

- *Don't give up on your dreams.*
- *Have confidence in yourself. Follow your heart. You can do it.*
- *Always think the strong way. Think, "I can do it." Live your life to the fullest.*

III. “Developmental Disabilities” and “Transition Services”

What is a Developmental Disability?

According to federal law, a developmental disability is a severe, chronic disability that is attributable to a mental or physical impairment or a combination of both. The disability occurs before age 22 and is likely to continue indefinitely. It results in a substantial limitation in three or more of these major life areas: self-care; expressive or receptive language; learning; mobility; capacity for independent living; economic self-sufficiency; or self-direction.⁷

In New York State, Mental Hygiene Regulations⁸ define a developmental disability in the following way:

“Developmental disability” means a disability of a person which:

- (1) (i) is attributable to mental retardation, cerebral palsy, epilepsy, neurological impairment, familial dysautonomia or autism;
- (ii) is attributable to any other condition of a person found to be closely related to mental retardation because such condition results in similar impairment of general intellectual functioning or adaptive behavior to that of persons with mental retardation or requires treatment and services similar to those required for such persons; or
- (iii) is attributable to dyslexia from a disability described in subparagraph (i) or (ii) of this paragraph; and
- (2) originates before such person attains age 22;
- (3) has continued or can be expected to continue indefinitely; and
- (4) constitutes a substantial handicap to such person’s ability to function normally in society.

New York State OMRDD uses the New York State definition of developmental disability to determine eligibility for services.

New York State OMRDD has responsibility for the prevention and early detection of developmental disabilities and for the comprehensively planned provision of services including care, treatment, habilitation and rehabilitation. OMRDD operates 13 regional DDSOs responsible for providing programs in one or more counties. Ideally, these offices provide specially designed person-centered assistance to each individual with developmental disabilities, and in partnership with consumers, families, private providers and local governments, seek to improve the quality of life of individuals and their families through the provision of quality, cost-effective housing, job training, employment and family support services.

⁷ The Developmental Disabilities Assistance and Bill of Rights Act of 2000

⁸ 14 NYCRR Section 624.20(u)

What Are Transition Services?

In New York State, "Transition Services" means a coordinated set of activities for a student with a disability, designed within a results-oriented process, that is focused on improving the academic and functional achievement of the student with a disability to facilitate the student's movement from school to post-school activities, including, but not limited to, postsecondary education, vocational education, integrated competitive employment (including supported employment), continuing and adult education, adult services, independent living, or community participation. The coordinated set of activities must be based on the individual student's needs, taking into account the student's strengths, preferences and interests, and must include needed activities in the following areas:

1. instruction;
2. related services (i.e. rehabilitation counseling, transportation);
3. community experiences;
4. the development of employment, and other post-school adult living objectives; and
5. when appropriate, acquisition of daily living skills and functional vocational evaluation.⁹

Federal and State requirements defining transition services for students with disabilities are consistent. The key difference is that New York State requires that transition services be provided by age 15 rather than 16, as federal law provides.

School districts in New York State are required to provide transition services for all students with disabilities aged 15 to 21. School districts utilize Individualized Education Programs (IEPs) to develop a strategic plan for incorporating transition services into the education plan for every student with developmental disabilities. Within the schools, a Committee on Special Education (CSE) monitors IEPs to ensure that students are prepared to fully participate in adult life.

What Is Transition?

Transition is a process, a service, and a right.¹⁰

A Process:

Transition is a process in which a student with a disability participates with parents, educators and others to create a long-range plan preparing the student for life after high school.

A Service:

The process of transition is closely intertwined with the provision of services that will prepare students for their future. These services vary from student to student, and range from

⁹ 8 NYCRR 200.1(fff); see also 34 CFR 300.43

¹⁰ Adapted with permission from The Transition Process, New York Lawyers for the Public Interest, 2003, www.nylnpi.org

teaching vocation and employment skills to daily adult living skills. Such services also include keeping students and parents informed about the agencies and options available to assist students further in the transition process.

A Right:

Transition is a right. It is required by the Individuals with Disabilities Education Act (IDEA). The IDEA requires that schools assist and prepare students with disabilities for their transition from high school. A student's Individualized Education Plan (IEP) is where a specific transition plan will be created, recorded and annually reviewed. In New York State, schools must begin working with students and parents on the transition process when the students reach the age of 15 years old.

Why is Transition Important?

1. Transitioning from high school can be especially challenging regardless of an individual's abilities. Yet, it has been shown that the earlier individuals begin planning for their transition, the more successful they will be.
2. The transition from high school is perhaps one of the most significant transitions in the life of a student with a disability. It is the first time that a student will be leaving a system where s/he was entitled to receive a range of services and supports. Once students leave high school they will no longer have these entitlements. Rather, they need to request or apply for services.
3. Statistically speaking, proper transition planning is vital: fewer than half of the individuals with disabilities graduating school today are employed. Transition services help individuals with disabilities make this vital link.

Who are the Key People in the Transition Process?

A student's transition plan is documented on the student's IEP. Therefore, all the individuals who are normally required to attend a student's IEP meeting will be present and important to creating the student's transition plan. However, the individuals who are vital to the creation as well as the implementation of the plan include:

- The student
- The parents
- School administrators
- Adult services providers

- **The Student:**

It is vital to encourage all students with disabilities to play an active role in their transition planning. Students must be invited to their IEP meetings and encouraged to express their ideas and wishes for their future. In addition, the interests and strengths of the students are key to creating IEPs that will not only interest the students, but that they will also be successful with.

- **The Parents:**

Just as the parents of students with disabilities play a critical role in creating their

children's IEPs, parents play the same role in establishing transition plans. Parents bring a unique perspective to the IEP meeting in their ability to speak about their child's capabilities outside of school. In addition, parents can speak to their child's possible need for independent living skills and other supports.

- **The School:**

Administrators within the school play the role of coordinating and implementing the student's transition plan's goals and services. It is also the responsibility of the school to ensure that parents and students are aware of the vocational agencies that can assist in the transition process while students are in school and after they have graduated.

- **Adult Service Providers:**

Agencies that provide vocational and other support services to adults are a key component in the planning process for the student. Their participation is vital for effective planning for supports the individual will need.

IV. What Ideally Happens as a Student with Developmental Disabilities “Transitions” from the World of Education to the Adult World?

The New York State Education Department (NYSED) and OMRDD, the experts in the field, the families of student with developmental disabilities, the students themselves, the providers of adult services, school district administrators and teachers understand what’s needed for successful transition. The elements are simple and straightforward:

- meaningful, informed interaction between consumers, their families and school personnel
- initiation of planning as early in the student’s academic career as possible
- timely and regular assessment
- planning and implementation of individual development plans geared to the individual student’s needs as he or she pursues hopes and dreams

In its publication, “Transition Services: A Planning and Implementation Guide,” NYSED, Office of Vocational and Educational Services for Individuals with Disabilities (VESID), notes:

The transition planning and service process encourages Committees on Special Education to look beyond the traditional educational focus of the IEP. The intent of transition planning is to enable youth with disabilities to live, work, and continue to learn in the community with supports if necessary as adults. The process of developing transition plans involves the following quality components:

- *Students are actively involved in transition planning and are supported in achieving their desired adult goals.*
- *Family members and other community service agencies, as appropriate, are informed, involved, and invested in transition planning.*
- *Transition planning addresses services and supports across all areas of one's life.*
- *A documented, sequential process is followed.*
- *Services and supports are provided in a timely manner as specified in the IEP, as agreed to by the student and family.*
- *Unmet needs are identified and addressed through an ongoing commitment to each person.*
- *The accomplishment of outcomes is measured in terms of students successfully achieving their post-school living, learning and working goals.*
- *Services provide maximum inclusion for students from linguistically and culturally diverse backgrounds.*

Putting these quality components into action may be easier to accomplish at smaller private schools, dedicated to serving students with disabilities. For example, at a local private school for students with disabilities, there is a transition classroom in which students are usually placed in during their final two years of school. Basic life skills are taught as well as other skills such as computer usage. Parents are consulted, together with their children beginning at age 14,

about interests. One parent told us, “It’s a team effort. They involve the students and families. They listen to the kids. There is a lot of one on one work. The teachers are very patient with the kids and develop excellent rapport. The school has taken me through the whole process.” She also noted that a job coach at the school took her daughter out into the community (community based assessment) where she did a variety of work including cleaning, envelope stuffing and general duties at the school bakery. Her daughter now works at a grocery store.

Unfortunately, as noted later in this report, this experience is atypical. For many students and families, teachers and providers, there are barriers at nearly every step of transition. Additionally, not all families would choose a small, segregated setting for their child. For parents who choose an inclusive environment at a public school where their child would have contact with peers without disabilities, the process may become much more complex.

V. How Information was Gathered and Reviewed

For this project to succeed, it was imperative to bring together youth with developmental disabilities and their supportive family members, educators, advocates, state agency personnel, advocates, providers of adult services, and community leaders. A Steering Committee¹¹ composed of people drawn from all these groups was brought together to shepherd the project, review data as it came in and, if possible, make recommendations to the community that were concrete and “doable.”

At a breakfast designed to introduce this project, over 100 people attended including: providers of adult services, educators, advocates, community leaders, individuals with developmental disabilities, and family members of individuals with developmental disabilities. The participants completed surveys analyzing the strengths and weaknesses of current transition planning.¹² Participants also identified “key contacts” in the community who should be interviewed individually as part of this process.

The Steering Committee’s first task was to identify key community resources to interview or to place on Expert Panels. In the weeks following the kick-off breakfast, five panels were convened to elicit expert opinion on how the systems connected to providing transition services were working and how those systems might be improved. The panels consisted of :

1. youth with developmental disabilities who had been through the transition process;
2. family members of youth with developmental disabilities who had been through or were going through transition;
3. school district transition specialists, teachers and administrators;
4. adult services and state agency personnel who provide transition services; and,
5. a group of experts from the city of Rochester who came from a variety of backgrounds.

With the exception of the city panel, each expert panel included representation from city, suburban and rural areas.

The Steering Committee has continued to meet once or twice monthly reviewing data, framing issues and exchanging viewpoints. To our knowledge, this was the first time that consumers, advocates, educators, agency representatives and adult services providers have sat at the same table to consider the challenges facing the provision of transition services and how to address those challenges. This report summarizes the work of the Steering Committee to date and invites the community to continue working to support students with developmental disabilities pursuing their hopes and dreams.

¹¹ Steering Committee Members are listed on Page 2.

¹² A list of those who attended the Kick-Off Breakfast is in Appendix 3.

VI. What We Learned

“I want a normal life--be a productive citizen, get a job, start a family.”

During the past six months, we held Expert Panels and interviewed: young adults who have been through the transition process, family members of students with developmental disabilities, teachers, school administrators, college faculty, adult services providers, personnel from state agencies, experts in the field, and community leaders. We included in our discussions people from large urban settings, rural areas and suburban sites who came from widely diverse economic, racial, family make-up and educational backgrounds. We wanted to ascertain what their experiences had been with transition; what worked, what didn't, who helped, what was needed to improve how transition is currently done. In this section we detail what we learned from talking with all these people. Wherever possible, we have quoted their own words (in italics) to better reflect their concerns. We have included a combination of oral and written quotes.

A. The Experience of Students with Developmental Disabilities

Most young adults we talked to did not hear the term “transition” or learn what it meant until their last year of high school. Several learned about transition planning from family members (*Teachers told my parents about transition.*) Some learned at school or learned about transition planning from a VESID counselor. Overall, the students believed their own desires were ignored:

- *School personnel were not helpful in my pursuing my dreams. They only knew what I could not do.*
- *I have a transition plan on my IEP but it is what school folks wanted. They never had a meeting with us.*
- *Attitudes make it difficult. I have had the same vision since 8th grade but because it isn't what school officials believed I should do they blocked my dream.*
- *I didn't ask for choices because they would have been group home and workshop choices—nothing I wanted to do.*

In addition to school personnel not supporting their dreams, some students felt lost after high school because they weren't sure what they wanted to do. They believe that more time is needed to decide what to do. *Taking a year break may be a good idea.*

Most helpful to students in transition planning were parents and those in their circle of support who often included family, friends, and agency personnel.

World of Work

For the most part, students we spoke with were extremely critical of the job training opportunities they were provided. *“They’ll put you in a job. If you don’t like it, you have to do it. I told them I wanted to work with little kids (in a day care setting). They put me in (a fast food restaurant) washing tables.”*

Some students however, found employers with a supportive attitude helpful. One noted, *“People at (my employer) were helpful . . . and will work with you and any disability you might have.”*

Transportation to and from jobs was an issue for many students and some noted there needs to be more training about para-transit and how to use it.

Students with a strong circle of support and/or job coaches fared better in work situations.

Hopes and Dreams

Some “Hopes and Dreams” identified by young adults we talked with:

- Make documentaries—working on a documentary about people with disabilities. Also wants to get a job with waste management because they pay well.
- Work in an office as a receptionist.
- Perform music, go on tour, open a recording studio, keep current business going.
- Make action films.
- Become a writer of children’s books, disability awareness books; perform volunteer work with senior citizens.
- *I have an IEP diploma. Now I want a GED and to go to college.*
- *I want a normal life--be a productive citizen, get a job, start a family.*
- *I want to be a lawyer, a prosecutor and ultimately a judge.*

We asked students what would have made it easier for them to move toward realizing their hopes and dreams. Some illustrative responses:

- If the school gave me more information about transition earlier.
- Take time to do other things -- then be allowed to determine what ultimately I wanted to do.
- *People who would believe in me.*
- *People sharing with me about more options and more adaptive equipment.*
- Learning more about the city and how to get around on (public) transportation.
- *I wish (the school) had placed me someplace that was more compatible for me. . .*

We asked young adults to think back about their transition from the world of education to the adult world and give some advice to developmentally disabled students who are currently in transition planning. Their powerful responses follow:

- *Don't give up on your dreams.*
- *Have people around you who believe in you.*
- *Don't take no for an answer. Even if people say you can't do something, you think bigger and believe you can do it.*
- *Be receptive to positive criticism.*
- *No matter what your disability is, you can achieve it (your goal). Learn what strengths and weaknesses you have and work with them. There are tools and strategies to help.*
- *Don't let your disability be an excuse.*
- *Whatever you choose to do in life, do it for you. Have confidence in yourself. Follow your heart. You can do it.*
- *Always think the strong way. Think, "I can do it." Live your life to the fullest.*

B. The Experience of Families Who Are Supporting and Advocating for Students with Developmental Disabilities

We interviewed parents of individuals with developmental disabilities who were currently involved with transition or had recently gone through the process. Their children ranged in age from fifteen to twenty-six and attended city, suburban, rural and private schools. Overall, parents felt ill informed and ill prepared to support their children in transition. They believe that unless someone is a champion for each child, demanding attention, information, services and help, transition services will not be provided. Finally they voiced concern that creative, person centered planning is discouraged, and placement into existing, traditional programs is preferred by school personnel. Again, wherever possible, we rely on the words of the family members to learn their concerns. Sentences appearing in *italics* indicate a direct quote from an Expert Panel member or someone who was interviewed.

The Most Difficult Part of Transition

For family members, supporting a child through the transition process can be a nightmare. So much is unknown.

- *Getting information and collaboration from school. I have yet to get a clear answer who the transition specialist is. The school personnel have been reluctant to work with transition.*
- *Not knowing what is available. Not knowing the questions to ask. Helping my son deal with the stress.*
- *The unknown—what is available in school to help with the process. What services are available and what is the school responsible for.*
- *I can't get "straight" answers on how to transition my daughter from school to the adult world*

And what is known is complicated, difficult, inflexible or unhelpful.

- *The "system" is not willing to try new options—does not see the value in what we want to do—inclusive post-secondary options. We have to create what we want—traditional day hab and res hab have too many restrictions!*
- *Professionals do not respect our vision and dreams for our children.*
- *The paper work is endless. The systems are complicated.*
- Finding transportation to get to adult programs is very difficult.
- Options for students after leaving school are very limited.

Parents were asked to reflect on their experiences supporting a child in transition.

What lessons did they learn?

- *It is never too early to start planning!! We are all life-long learners, continually seeking knowledge, experiences, etc. And people with disabilities should have the same opportunities.*

- *There are options which are available at younger ages. Information needs to be disseminated much more timely.*
- *Start early, there is a process.*
- *Find out what all your options are.*
- *The parent/guardian must be your child's best advocate. Be a "squeaky wheel."*
- *The child has a right to access available programs and services.*
- *The parent and the student have to "do it" themselves.*
- *It doesn't work like you plan.*
- *Lots of systems and programs are based on disability. If your child doesn't meet the definition, you won't get any help.*

What advice would they give to someone else about their family member's transition?

- *Don't just accept what agencies and school districts offer if you want something different. Be brave and create your own solutions.*
- *Get Person Centered Planning. This is a facilitator to help get started. Requires educating yourself (need access to info and workshops earlier).*
- *Have as many people involved who know your child. They have a completely different perspective and ideas to offer.*
- *That they observe all the programs their district is suggesting before making a decision.*
- *Start early—age 14 or so. The process takes a long time. Preparing your child to be ready and accepting takes time. Find someone to help who knows the "system."*
- *Be as knowledgeable as possible! Continue to advocate!!!!*
- *"Do it" yourself.*
- *You are in charge. Keep pushing for what you want.*

What Else Is Getting In The Way?

- *Bureaucracy is rendering us all impotent.*
- *I'm scared for my son. I'm scared for a lot of the kids out there. I'm trying to get my children life skills but they are fighting me every step of the way.*
- *We expect kids with disabilities at 18 to know what they're doing while kids without disabilities may not know what they want to do for many years.*
- *Time put in by family members is astronomical and exhausting. Parents actually lose their jobs trying to keep up with everything they need to do for their child.*
- *Level I and Level II assessments are unhelpful. One student with a strong desire to work with the elderly had auto body finishing suggested to her after a level II assessment.*

Working with School Districts

- *No one in the school district wants to be helpful in transition. That's one more piece of work for me.*

- *No one in the school district “gets” transition. We’ll worry about that junior year. Teachers haven’t been educated as to what the options are. There is a huge disconnect between what is supposed to happen and reality.*
- *School districts name transition specialists with little experience in the field. There is high turnover in that position.*
- *To this day I don’t know who the transition specialist is.*
- *School keeps saying, “VESID” will handle transition.*
- *My school district didn’t have a clue.*
- *The schools give you no information. You have to learn from other parents or groups.*
- *Local schools have an incredible amount of control over our lives. The system stinks. The people that persevere make it work for individual children. The school is actually a hindrance. Parents who can’t devote time and energy within the school district will see their children with limited options.*
- *CSE meetings are rushed.*
- *They can’t think out of the box.*
- *We’re being told our transition plan is unrealistic. “Your child doesn’t have the ability to do that.” Well, why not look at the pieces of the job he can do?*
- *Parents trust the system. The school district says, “This is our job, we’ll take care of your child.” Then 18 comes along and you have no idea what to do.*
- *If a parent doesn’t have time to do the advocacy the child doesn’t get the individual attention and falls through the cracks.*
- *School district doesn’t relate to anything else in the community.*
- *School districts do not disseminate information to parents about programs. They told me to wait until junior or senior year (to work on transition.) Transition needs to start much earlier.*
- *The School districts know how to get kids into college. They never have a system for our kids.*
- *They thought my daughter’s hopes and dreams were a crock. All they were prepared to do is to funnel you into a group home or sheltered workshop.*
- *She’s graduating and where is my child going?*

Who or What Helps the Transition Process?

- *You’ve got to be a squeaky wheel. You have to make the child real. To them he or she is a number.*
- *Anything that’s ever happened is because we made it happen.*
- *It takes so long to figure things out. Talking about career, hopes and dreams can start very early—kindergarten, pre-school. Exposing kids to options is so important.*

What’s Needed?

- *More collaboration is needed. There is no sense of team for the child. Someone is needed to pull everything together. Could it be the transition specialist?*

- *How about a “transition concierge?” Or facilitator in school who parents could work with.*
- *We need teachers who are trained on transition.*
- *Need to send info directly to parents to inform them about events, meetings, etc. More often information is sent to school which may or may not send it on to parents and may or may not do so in a timely manner.*
- *Need to define roles. What exactly is the role of the transition specialist? It should include knowledge of, and the ability to interact with, the community outside of school. Involve parents on CSE, transition team, etc.*
- *If the system worked, we wouldn’t have to search for everything: the school would be automatically linking parents up.*
- *Transportation is a huge issue. What happens after you graduate? The transportation service I use is wickedly cruel. You have to lie and cheat to get them to pick you up. State funds for transportation are needed.*
- *There needs to be more exploration of options. Instead of saying just “your child can’t do that,” say “what are the barriers? How can we minimize or remove them?”*
- *Schools need to tell students about other options. For example, Options for People Through Services (OPTS—through NYSOMRDD). These options need to be explained early because it may take several years to develop.*
- *Treat people as individuals. Respect people’s hopes and dreams. Don’t write them off.*
- *Funding and trained staff. Make transition planning a priority for schools. It isn’t now.*
- *People have to understand that, “transition is not an event, it’s a process.”*
- *School needs to sit down with student and parents to “envision a plan” that drives goals and identifies a set of skills and steps toward achieving goals. A plan is not an outcome.*

C. The Experience of Educators

Educators from urban, suburban and rural school districts provided insights on transition. Most were very clear on their role in the transition process and the need to begin planning early.

- *As a school counselor, I am part of a team involving students, parents, teachers, school districts with transition planning. I assist students, parents with career exploration, standardized testing, college/vocational searches, info, “skills for life” instruction (post-secondary skills training), development of transition goals, credit info. I become involved as early as middle school with career surveys.*
- *In my role as a transition coordinator, I become involved as early as 6th grade--the more significant the disability the earlier I become involved. The latest I should be involved is in 11th grade.*
- *We work as a team in the transition process: case manager, school psychologist, special ed teacher, student and parent.*

How Effective Is Transition Planning For Students And Their Families?

Educators recognize that the effectiveness of transition planning varies widely. When considering the percentage of students for whom transition planning is successful, teachers and administrators provided answers ranging from 25% to 95%. Why do some efforts succeed and not others?

- *Family participation is the prime factor in the effectiveness or ineffectiveness of planning.*
- *For some, it is wonderfully effective given the processes that families/students have become involved in . . . i.e. person centered planning.*
- *It depends on the student involved, the families, and the circumstances. Transition needs vary because of nature of needs, motivation of student and family, thinking “outside the box” in terms of programming.*
- *Transition planning is as effective as concerned members are informed. The more knowledgeable individuals are about transition, the better they are equipped to utilize the services.*
- *For kids with developmental disabilities and mental health issues, systems struggle to meet day to day challenges. Planning for transition to adulthood is an issue rarely done well.*
- *Depends upon the student—the more complex the need, the more difficult is the match.*

What Gets In The Way?

Educators found barriers in almost every part of the system:

- *Silos of services* have been set up which don't work well together. There is little collaboration, more of a hand-off when the student leaves the academic setting.
- In schools our systems are geared toward academics, but not for practical skills that will let individuals function independently or in sheltered workshops. Schools seek to meet state education standards; vocational transition becomes a lower priority.
- Residential programs have long waiting lists. "Day Habs" and workshops are easier to access.
- Pigeon-holing. *You find yourself filling out the IEP so students can fit in to a particular program, rather than doing what's in the best interests of the student. Fundamental change is needed. The system is broken. We get good outcomes for kids who fit the system. However, we need to see kids as kids with needs and have systems adapt to respond accordingly to them, instead of fitting (even force fitting) kids into the requirements of programs.*
- The adult system has no incentives or resources to develop relationships with schools. *When a relationship develops, it is because of individuals wanting to make it happen, not the system.* For example, adult services providers would have to use a personal day if they wanted or were needed to attend a CSE meeting.
- There is a major access issue with VESID.
- There is *an unbelievable turn-over in service coordinators. We spend a lot of time catching up with new people. Service coordinators and transition coordinators are closest to the students and critical to successful transition. Yet we often have our least experienced staff in those positions. It makes no sense.*
- There are no set requirements for the transition coordinator position.
- Parental Involvement. *I have a really hard time getting parents in. It's frustrating to have only three families show up for an evening transition program. I send home mailings constantly and then a parent will call and ask "Why haven't I heard from you?"*
- Rural school districts have fewer resources.
- More time is needed for staff development.
- More time is needed to visit program sites at the larger provider agencies.
- *Because of a scarcity in resources, the focus is on compliance first, which moves us away from individual planning or using creative programs like OPTS.*
- *There is a genuine disconnect between many of the skills taught in schools and the ones needed in the community.*
- *Full family participation makes it work; the less the family is involved/invested, the less successful is the process.*
- *Many things can get in the way: no parental follow through, poor follow through by service coordinators, not being able to find the right placement after they leave school, students change their minds, finding the time and the personnel for instruction during the school day.*

- *Not knowing all of the agencies and what they do, failure to begin planning early enough, unrealistic planning and goals (student and parents), etc.*
- *Dept. of Ed. responsibility stops at age 22. They are accountable to develop the transition plan but not for its outcomes after kids leave school. Adult providers/systems are not connected with kids early enough due to funding limitations.*
- *Apathy, lack of understanding why future planning is important. Often students live in the moment, can't picture or deal with the future.*

Which Students “Fall Through The Cracks?”

- *Dually diagnosed individuals are passed back and forth between agencies. Some students need services from both Office of Mental Health (OMH) and OMRDD.*
- *Students with autism or Asperger syndrome may be too high functioning to qualify for developmental disability services. However, even if they have the required academic ability and have graduated with a local and Regents diploma, there is little likelihood of success in college because of their limited social skills. 18-21 year olds need social skills development.*
- *It's a challenge: learning to speak and understand the language for each agency (VESID, OMRDD). IEPs need to be written according to the right language.*
- *Agencies are taking fewer youth with “behavioral management” issues.*

What Changes Do You Recommend?

Educate. Educate. Educate. Increase the understanding of school personnel and families about programs offered by adult services providers and how to access them. Increase the understanding of adult agencies and programs about the needs of individuals leaving the education setting. Get everyone—families, schools, adult services providers-- talking and working together.

- *Systematically there need to be holistic changes which offer pertinent, on-going information and training, and allow the schools/adult agencies to connect, meeting the needs of students.*
- *Create a website of all the agencies that is maintained and updated monthly or more often. The website would ask for a profile of a student and then generate a list of agencies that meet the needs identified in the profile.*
- *Create brochures for each adult program clearly defining the services provided by community agencies.*
- *Encourage service providers to visit schools and education personnel to visit program sites. Provide parent education on adult agencies.*
- *Get parent input and buy-in—get them to collaborate.*
- *Increase student and parental understanding and involvement.*
- *Engage employers and educators on multiple levels (i.e. identifying trends, needs, shortages, communication, etc.) making them partners in transition planning with accountability.*

- *Provide students and family members a list of school transition team members with clearly defined roles.*
- *On-going professional development and staff involvement play an integral part of effective transition services.*
- *Add resources or make better use of those that are already in place.*
- *We need a list of agencies that can help in multiple counties together with a list of resources—what is out there, so we are not always trying to hunt for and understand everything.*
- *The assignment of a transition counselor to each case would be huge.*
- *Increase support for teachers to weave career/transition activities into the curriculum.*
- *Contract with VESID to be job coach for VESID eligible students.*
- *Lower the turnover rate in the positions of service coordinator and transition coordinator by improving job satisfaction. When hiring a transition coordinator, look for someone with vocational rehabilitation and experience working with business. Develop a job description with defined roles.*

Evaluate schools and adult services providers meaningfully.

- *Clearly delineate and coordinate three stages of transition: k-12, pre-adult, adult services with accountability throughout.*
- *Rate school/providers by success in transition outcomes.*

Empower students and families by increasing their understanding of transition as early in the students academic career as possible, increasing their access to services, and reducing the amount of paperwork.

- *Provide a unified source for information. For example, create a centralized website for schools, adult providers and families. Everything else is on the web-- why not this kind of information? The website should enable you to punch in a student profile and kick out agencies that will provide services.*
- *We need to create an umbrella agency that brings all services together and makes every part of the system accountable. Creating a central agency will help implement the principles of self determination-- person centered planning.*
- *Informational meetings, one to one planning with transition team, visitations to adult programs earlier in academic life.*
- *Prepare and distribute a book of “Questions I Wished I Asked,” written by parents.*
- *Have service coordinators involved during transition planning to advocate and assist with transition plan.*
- *Streamline the system. Use one process and one application form to apply to adult programs.*
- *Better communication and more agency fairs, workshops, and presentations at individual schools so parents know what is available to them.*

- Give funding directly to individuals in the 18-21 year old bracket to use on adult services that best supports their hopes and dreams.

What Educators Need And Expect From Adult Services In Transition Planning

Adult services providers need to clearly state the services they offer with time frames and key contact people. They need to visit our schools more and invite students and teachers to visit them. They need to be better prepared to serve our students with more programming options. We expect that adult services providers will:

- *Be aware of our type of students and their needs ahead of time (at 18-19 years old to graduation at 21) to better prepare.*
- *Have a clear continuum of services with “skills” needed at each level.*
- *Have a variety of “dayhab” groupings to place different types of students.*
- *To use some of the visual supports sent to students to help in their success.*
- *To have students visit and spend time there (at agencies) to informally evaluate at 20th year to see if it’s a good match.*
- *To have adult program staff come to observe students and/or set up transition planning meetings to help ease students into programs.*
- *Understand that transportation can be an issue. Helpful if adult services had waiting lists for residential and dayhab programs.*
- *Provide assistance in having “systems” come together . . . Agencies can help by providing information to families so that families see “systems” collaborating.*
- *Provide direct contact to schools via phone, e-mail, mailings about services. Presentations at schools about organizations, programs, services.*
- *Maintain consistent personnel. Not uncommon to have annual CSE and have new service coordinator each year. Parents shouldn’t have to train the service coordinator.*

D. The Experience of Adult Services Providers

Adult services providers largely see themselves as excluded from an integrated transition process, although the potential is there to integrate them.

- *There is a lack of information and accessibility to transition coordinators.*
- *I'm a bit on the outside—but I don't see the process as integrated as it should be considering we are speaking about a person's life.*
- *We are rarely included directly in transition planning (through CSE meetings). We are only included if the students or parents invite us. When there are multiple disabilities, blindness tends to get very little attention.*
- *Our agency staff can be—if transition planners link students to us. We can continue the transition planning into vocational and community support services.*

Overall, providers view transition planning for students and their families to be very ineffective.

- *I believe many people are unaware of the agencies that provide services for youth in transitioning. I have little connection with the planning side.*
- *Generally students come to us at the time of need but rarely early enough to effectively plan.*
- *If school district is invested it can be effective.*
- *Because of lack of family participation or misinformation the process has not been very effective. Many parents aren't informed of options.*
- *It doesn't always seem that the teachers are aware of the process.*
- *I often hear of either a lack of planning or delayed planning. I hear of parent concerns regarding their lack of awareness of services beyond school. It depends on the level of involvement/advocacy by the parents. It also varies among school districts.*
- *The students that I have worked with, I have not seen one person transition smoothly.*

Providers are especially concerned that they do not have data from schools on the number and the needs of students who are leaving the academic world.

- *We don't know how many kids are exiting in a given year. This is a big problem for planning!*
- *We don't have these statistics. We are dependent upon school to bring referral to us, despite parent nights, fairs, etc.*

Specific Problems in the Transition Process

Communication

- There is a lack of communication across the system.
- Parents need to know what and where to access information.

Coordination

- *We haven't been able to adequately coordinate education and adult services.*
- *It's a matter of breaking through bureaucracies.* For example, stop the infighting between OMRDD and NYSED.
- Parents aren't aware of services available and may not have a service coordinator. Who writes IEP or sets expectations?

Timing

- The last six months is not the time to “throw” a plan together.
- Early intervention is essential and rarely happens.
- With OPTS you need nine months to a year to put a proposal together and funded.
- Some schools will only let you see their seniors, or maybe their juniors in May of their junior year.
- Student is lost at 14 if there is no transition plan in place.
- Time is needed to secure funding stream. Funding can't be taken for granted.

School Districts

- If the school district is not committed to transition, it will be reflected in the kind of process that gets implemented and how students are in making the transition.
- *We are reliant on transition coordinators who may not care. It's amazing what they don't do.*
- *School districts are not held accountable.*
- *Who are the transition coordinators at the school districts?*

Entitlement versus Eligibility

- There is a *significant cultural split* between the education world and the adult services world. *Entitlement versus eligibility* confuses parents.
- Parents think that *because my child has a special need* there is an obligation for support from the state.

No Hard Data

- We can't plan without knowing who is coming out (of the schools) and what they want/need. *Give us information on who is graduating, with what needs?*
- OMRDD doesn't know how many students Board of Cooperative Educational Services (BOCES) is graduating.
- *We are frustrated. In order to create programs or services we have to know what's out there.*
- Determining needs of students is sometimes a problem because of privacy rights.

Workers in the System

- *It's primarily a people works issues—not a systems work issue.*
- *If you have a good case coordinator or a good advocate the system can be made to work for you.*
- *We have to be careful about the demands placed on teachers. The ones who do it well (transition) do it at personal expense.*
- *Transition coordinators don't tour job sites.*

Youth and Families

- There are many families who don't have the resources or the ability to manage transition.
- You need to build trust with parents and students which requires time and access.
- The focus needs to be on what the student really wants rather than what's available.
- Follow through is crucial and parents may not have the wherewithal to do so.
- Youth who face a language barrier *often fall through the cracks and end up hanging out on the street or staying at home.*
- Parents don't always know their rights.

Overall, Why is Transition Planning Ineffective?

Similar to the educators, providers saw barriers with every component and every player in the transition system, including students, parents, teachers and providers. They also highlighted poor communication, the lack of inclusion of all key players, and the differences in the “entitlement” world of education and the “eligibility” world of adult programs.

- *Communication, planning, significant differences in the school and adult systems. “We don't speak the same language.”*
- *Lack of participation, lack of information, eligibility issues.*

- *Lack of planning, support and follow through.*
- *Schools/families may not have pursued OMRDD eligibility.*
- *Families may hold out for just one program.*
- *Kids may not be not ready to transition to less supported work/day habilitation services.*
- *Kids exiting high school before eligible for OMRDD funding.*
- *Lack of preparation, time crunch, lack of investment.*
- *Students' and parents' follow through. They may begin the process of transitioning and find it too time consuming. Must keep students motivation triggered.*
- *Insufficient school administration investment in process, philosophy and educational staffing and funding of transition activities.*
- *Lack of understanding of parents between funding resources available to school and adult services.*
- *Lack of follow-up by service coordinators and teachers.*
- *Lack of expectations and understanding Lack of financial resources. Money doesn't follow the person. No accountability.*
- *Communication, lack of understanding of the system.*
- *Poor communication, lack of inclusion of all key players. Students are not always given the opportunity to provide input.*

How Can Transition Planning Be Improved?

Many of the providers' suggestions mirrored those recommended by educators and families such as increased communications, training for everyone, more accountability, increased cooperation and collaborative efforts. They also agree that planning must begin earlier and that more opportunities need to be developed for students leaving secondary education settings. How well the transition process works depends on: the school district, teachers, the service coordinator, the student, parent involvement, and whether there is an advocate working with the student. *The more the parent advocates the more likely they are to have a successful transition experience.* The providers strongly agree that without a champion, the ability of the student to understand and navigate the transition world is extremely limited.

Here's what providers believe are necessary to make transition planning more effective:

- *We need some type of centralized point of entry/resource that families and teachers could go to – would be helpful in connecting all services. We need agency/ provider universal forms as well as a designated contact person for service coordinators and parents.*
- *Education for students, families, educators. Clear expectations and roles. Accountability on all ends. A designated independent transition agency! More communication among all the players involved.*
- *18-21 year olds need more work programs or something "different" for the students.*

- *Minor adjustments are necessary in marketing and advertisement. Far too often people are not aware of the services available.*
- *The transition planning is hit and miss, as are most systems, it is dependent upon the advocacy of the parent. But not all parents are advocates. Not all parents know/understand OMRDD system. They need guidance, direction from an early (14 -16 years) stage and they need straight talk (no early exit, non-entitled services, etc.)*
- *OMRDD and SED need to talk. More coordination between OMR and VESID—VESID can work with students who exit before 21. The system needs changes so that everyone is on the same page—VESID, school district, OMRDD.*
- *Early intervention. Planning needs to start when the person is 14-15 or 16-17. Not at 21 and 2 months away from graduation. There needs to be a time—14, 15 years of age—where everyone gets together (transition team) to start the planning for individuals. If parents are not involved in the process their children can be over-looked*
- *Develop clear roles for everyone involved in the transition process and spell out what's expected from each.*
- *Some sort of centralization thru DDSO at age 14. "Who will need services when?"*
- *Educate service coordinators.*
- *Identify an independent agency for school accountability.*
- *Parents must be active partners—they need educating to fulfill their role. Students are being pushed through the system without knowledge of or access to supports and resources.*
- *Family Education, single point of contact, sharing of information regarding who is aging out.*
- *Joint planning processes, start earlier, make a commitment.*
- *Transition staff at schools should be visible and familiar with community services for young adults. Districts should consider purchasing transition services from "transition experts" who can be devoted to transition planning and have familiarity with service systems.*

Recommendations to improve access to information focused on centralizing where information can be obtained and encouraging more interaction among educators and providers:

- *There should be some type of county wide transition office/clearing house where parents can get information on all agencies, services, work programs, eligibility, college, etc. This may be funded by a collaboration of SED/VESID/OMRDD/school districts and other resources. IEP students need extra support to make the change.*
- *Perhaps an annual listing should go out in some sort of media capacity which informs individuals of all the agencies out there, all the services available, qualifications and requirements.*
- *Increase training to all providers, teachers and districts. Districts should be responsible to educate all about the available services.*

- *Increase presence of agencies in schools at an earlier time.*
- Give presentations of services available at city, county levels during budget renewals and at teacher in-service training.
- Increase parent education re: the process, supports, options, etc. Utilize the internet for information posting and sharing and actively market the availability of the information. All information provided to parents should be in “plain English.”

More Ideas to Consider

- Attach dollars to the person between ages 18-21. Let the individual decide how to best utilize funds to advance their transition plan.
- Be more flexible in allowing students to leave school at 18 and start receiving assistance from VESID.
- Create checks and balances in the system that will let everyone know who is accountable and what is happening.
- Add a “tickler” to CSE beginning at age 14– will this student be eligible for OMRDD?
- Create an “Independent Transition Office” to keep everyone in the system accountable.
- Require schools to have a dedicated transition coordinator.
- Give parents a “single contact person.”
- Provide more in-service training for teachers.
- Push system to make more options available.
- Create a “checkpoint” at age 14-16 reviewing the transition planning done for each student in the school district. Without an adequate assessment and review, withhold monies given to the school district for the student.
- Create an annual report identifying the number of students in each grade within a school district with disabilities and identify the type of disabilities.
- Develop a system similar to “No Child Left Behind” to aid accountability.

E. The Experience of City of Rochester Experts

A panel composed of staff from the Rochester City School District (RCSD), Boys and Girls Club, Office of the Mayor, Community Place of Greater Rochester, and Finger Lakes DDSO was asked to focus on challenges unique to providing transition services to people with developmental disabilities in the city of Rochester.

Unique Challenges

1. Conditions of poverty may lead to family keeping child at home to get SSI benefits which could be a barrier to accessing residential and other programs.
2. Lower literacy rate in the city can affect families' ability to understand and access services. DDSO staff believe that there is a large percentage of city students who never even contact DDSO or adult services providers.
3. Gaps in the system:
 - More students are leaving before the age of 21 and are caught in limbo. ("Kids want out at 18.") Students may not have information on how to access services; assessment and medical records may not be within the most recent three year period when they do apply.
 - Lack of uniformity in measures and tools to assess adaptive behavior (needed to establish OMRDD eligibility)
 - Perception that life skills can only be taught if noted in the IEP
 - Psychological evaluations are not regularly updated
 - Assessment tools used by RCSD are not accepted by OMRDD;
 - Some families do not have doctors that can be contacted for diagnosis, putting strain on Article 16 clinics trying to get diagnosis
4. Size of the school district makes it difficult for agencies to reach out to the many schools.
5. The term "developmental disabilities" has a completely different meaning to educators than it does for adult services providers.
6. The term "services" may be seen as a negative term in African-American communities. Use of the term "services" may lead to reactions such as "my child is not crazy," or "nothing wrong with me."
7. Many students blend in with all the other students, effectively hiding disabilities.

What's Needed

1. Improved marketing, communications and public relations:
 - Create messages that break the cultural stigma and enhance the humanity of the individual.
 - Attach a concrete goal to programs given by agencies, i.e. “If you go to this program now, you will get a job next summer.”
 - In marketing, focus on concrete activities that will result in today or near-future benefits. Use media including WDKX, KISS that the kids listen to.
2. Ask churches to become more involved in providing information and communicating with parents.
3. Connect DDSO staff with a contact person at each high school.
4. Find a way to release information to agencies about students without violating HIPAA regulations.
5. Because school staff can be overwhelmed by “people trying to help,” create a single point of entry—a consortium of agencies with one contact person to work with each high school. As a result, the high school contact will not have to work with a plethora of agency staff.
6. Use common language in education and adult programming.
7. Subsidize employers who hire kids with developmental disabilities; kids need incentives to stick with work programs.
8. Find new ways to reach parents (“open houses have not worked”):
 - Some parents are afraid of their teenagers
 - Parents have a lot of reasons for not showing, up including denial that their child has a developmental disability

The overall view of this panel -- that students in Rochester are less likely to connect with or be actively involved with transition services -- is supported by national research.¹³

Need for Different Case Management

A case management study¹⁴ found that to meet the needs of individuals with mental retardation and developmental disabilities and their families living in urban settings, a non-center-based model of case management was needed. In contrast to traditional case management in which families and consumers come to the case manager and most service coordination is done by telephone or in meetings at the case manager/social worker's worksite, the case manager in a non-center-based model is mobile and able to meet the consumer and family in their domains.

¹³ Pamela Loprest and David Wittenburg. 2005. "Choices, Challenges, and Options: Child SSI Recipients Preparing for the Transition to Adult Life." Report to the Disability Research Institute

¹⁴ Ardito, M., Botuck, S., Freeman, S.E., & Levy, J.M. (1997). “Delivering Home-Based Case Management To Families With Children With Mental Retardation And Developmental Disabilities” Journal of Case Management 6(2), 56-61.

Employment Opportunities

While supported employment programs are available in metropolitan areas (within and outside central cities) as well as non-metropolitan areas, urban youth have fewer employment options. The National Longitudinal Transition Study (cited earlier) examined the employment outcomes for urban, suburban, and rural youth with developmental disabilities. The study found that:

- Urban young people with mental retardation were less likely to be employed full time or part time (16%) compared to suburban (26%) or rural youth (20%).
- For young people with all disabilities combined, the employment rates were higher than for young people with mental retardation, but followed the same pattern (urban youth 30%, suburban youth 46%, and rural youth 41% employed).

Lack of research on urban young people and such factors as gender, race/ethnicity, and socioeconomic status is a gap that limits our understanding of resource allocation, access, and equity in the implementation of supported employment programs. However, advocates and self-advocates have expressed concern with the "underachievement" of supported employment programs and have called for modifications (social integration, career choices, and employment retention, etc.) that will benefit persons with severe developmental disabilities. Despite increasing demand, decreased federal funding and state budget crises squeeze program capacity. The provision of high quality services is threatened and services must be rationed. The current economic and political climate promises further challenges to the employment opportunities of urban young people with developmental disabilities from differing racial/ethnic backgrounds.¹⁵ Transportation barriers that make it difficult to get to jobs located in the suburbs and limited access to child care are other complicating factors.

¹⁵ Journal of Rehabilitation, Jan-March, 1996 by Arie Rimmerman, Shelly Botuck, Joel M. Levy, Jacqueline M. Royce

VII. Major Findings

Taken together, all the voices of the stakeholders in transition planning reveal eight compelling findings:

- A. There are two very different worlds involved in transition: the world where students with developmental disabilities are “entitled” to an education that meets their needs, and the world where adults with developmental disabilities may be “eligible” for programs and services. These worlds know too little about each other, use different vocabulary, have different cultures and are connected in a haphazard way. Each world will significantly benefit from increased training, support and collaboration with each other. Students with developmental disabilities and their families must have the skills, knowledge and support necessary to be able to succeed in both worlds.
- B. While federal and state laws and regulations are in place to support successful transition, they are not consistently enforced or implemented.
- C. Extensive research has been conducted to determine transition practices that make a difference for students. These practices include¹⁶:
 - 1. Student participation in the planning process
 - 2. Parents as active and informed partners
 - 3. Transition planning early in the secondary school years
 - 4. Quality vocational training
 - 5. Meaningful community based work experiences
 - 6. Effective, systemic and sustained interagency collaboration

Implementation of these practices remains extremely challenging.

- D. Parents are poorly informed about transition, school district procedures, and choices available to their children after leaving high school. Parents, teachers and providers are often unaware of outstanding resources - highly competent, caring professionals and well designed materials - available to assist them. Cultural differences further hamper communication efforts.
- E. Too few choices are available to students as they move from the world of education to the world of work or higher education; those choices that are

¹⁶ See, for example, *The Transition Experiences of Young People with Disabilities: A Summary of Findings from the National Longitudinal Transition Study of Special Education Students*. M. Wagner, J. Blackorby, R. Cameto, K. Hebbeler, and L. Newman. Menlo Park, CA: SRI International, 1993; DeFur, Sharon, *Designing Individual Education Program Transition Plans*. Eric Digest #E598, 2000; Mueller, Roberta, *Missed Opportunities: The State of Transition Services for Youth with Disabilities in New York City*. New York, N.Y. New York Lawyers for the Public Interest, Inc., 2005. West, L., Corbey, S., Boyer-Stephens, A., Jones, B., Miller, R. & Sarkees-Wircenski, M., *Integrating Transition Planning Into the IEP Process*. (2nd ed.) Reston, VA: The Council for Exceptional Children, 1999.

available must largely fit into a traditional mold. Limited funding models make even the most creative choices difficult to achieve. School and agency personnel too often focus on fitting students into an existing adult program rather than listening to the student's interests, skills, hopes and dreams.

- F. The quality of services provided to students and their families varies widely from school district to school district and even within school districts.
- G. Planning for the needs of students aging out of mandated educational services is woefully inadequate. The number of students with developmental disabilities leaving school districts each year is unknown. Information is not readily available on their needs.
- H. Without a "Champion," an advocate working with the student, the chances for achieving a successful transition are enormously reduced. The state agencies charged with overseeing transition systems are complicated, not coordinated with each other, and often work at cross-purposes. In the face of such bureaucracies, even the most assertive, educated and responsible parents struggle.

VIII. Recommendations

In making recommendations, the Steering Committee had certain criteria. Are the recommendations concrete and “doable” in the near future? Will the recommendations be conducive to bringing people from all parts of the transition universe together to solve problems collectively? Does the local community have the power to implement recommendations or does the power to do so rest elsewhere? Will the recommendations have an immediate and dramatic effect, visible to the community, if necessary changes are implemented? Finally, the Steering Committee considered the cost of implementing recommendations. Professionals already at work can implement many of the recommendations without significant funding, by improving collaboration and cooperative transition efforts. Other changes will require grants to support pilot projects. With these questions in mind, the committee developed the following priority recommendations:

Priority Recommendations

1. Improve overall communications between school districts, adult services providers and families with specific activities. For example:
 - Implement a pilot project to demonstrate effective planning and sharing of information between school districts, OMRDD and adult providers
 - Develop a common application to be used for adult services programs
2. Provide training for school district staff, families and adult services personnel. For example:
 - Create a pilot training program for transition “champions”
 - Increase dissemination of informational resources already available
 - Develop “Key Questions” list and check lists to assist families in planning and implementing transition efforts
3. Advocate for systemic changes. For example:
 - Enhance curriculum at local colleges to better prepare future educators
 - Advocate for more flexibility to allow community-based experiences as part of students’ school programs
 - Standardize definitions and terminology used by schools and adult service providers
 - Conduct outreach to area colleges and universities to facilitate post-secondary opportunities for students with developmental disabilities

The following is the full set of all the committee's recommendations.

Comprehensive Recommendations

Recommendation 1. Increase Collaboration between the School Districts and Adult Services Providers

Goals: Increase and regularly update information provided to adult service providers on what students are coming out of the school districts and their needs

Increase and regularly update information provided to school district personnel on available adult services programs and their requirements

Strategies:

- a. Convene a work group composed of representatives from DDSO, NYSED, school districts, families, and adult service providers to develop, monitor, and implement communication systems designed to provide this information
- b. Use existing groups like the Regional Transition Coordination Site network to support these efforts
- c. Use consumers and families to keep a person-centered focus to these organizational processes

Recommendation 2. Improve Communications from Schools and Providers to Consumers and Families

Goal: Have information readily available to consumers and families to allow meaningful and appropriate involvement of consumers and families at every step of transition planning and implementation

Strategies:

- a. Increase dissemination of informational resources already available such as, "Planning for When the School Bus Doesn't Stop Here Any More," a publication of the Midwestern Regional Transition Coordination Site
- b. Create a central (web-based) clearinghouse of information for consumers
- c. Standardize definitions and terminology used by schools and adult services providers
- d. Develop a common application for transition (similar to the one used for residential programs) that can be used in applying to non-residential programs

- e. Develop “Key Questions” list and check lists to assist families in planning and implementing transition efforts
- f. Create lists of key questions for consumers and families to ask agencies
- g. Teach consumers and families how to interview an agency to get the information they need
- h. Create check-lists of things to do and timeframes
- i. Clearly define roles and responsibilities in the transition process

Recommendation 3. Increase and Improve Transition Training and Education for all Stakeholders

Goal: Ensure that students, family members, educators and providers are fully informed with the skills they need

Strategies:

- a. Create a pilot training program for transition champions
- b. Provide more in-house and professional development training for teachers and providers on a wide range of transition topics including:
 - Transition “Philosophy,” i.e. achieving the hopes and dreams, of every student
 - There are no cookie cutter approaches to transition planning. We need to work with one student at a time
 - How to work more effectively with students and families
- c. Provide more parent education on a wide range of transition practices including:
 - the difference between entitlement and eligibility programs
 - training on options available to students after their high school experience
- d. The development of training efforts must include meaningful involvement of consumers and families all the way through – identifying the needs, working on the solutions, testing and fine tuning the training programs that result
- e. All training efforts should include a “train the trainer” component
- f. Enhance curriculum at local colleges to better prepare future educators to assist with transition

Recommendation 4. Place Transition Specialists in Each School District¹⁷

Goal: By making transition specialists available to each school district, reduce school districts' struggles with:

- service coordinator consistency
- providing consistent contacts within the district
- educators who don't know the adult system
- consumers who don't know the adult system

Strategies:

- a. School districts: Find a champion on the school district administrative staff to oversee this effort
- b. NYSED:
 - Identifying a career track for this
 - Develop Certification requirements
 - Add to curriculum
 - Develop performance metrics holding the school districts responsible
- c. State agencies such as OMRDD:
 - Implement and coordinate a Transition Action group (TAG) that meets to share information and tools
 - Fund pilot project building on efforts already underway in Monroe County
- d. Create a pilot training program for transition champions

¹⁷ Transition Specialists:

- are trained and paid to know the transition systems, the agencies and the funding laws
- know what services are offered where
- know what agencies are "open"
- understand that the job calls for a bridge-builder and champion (especially when the consumer has no other effective support)
- are responsible for early (in-service) and continued contact
- provide person centered transition planning
- serve as the keeper of the consumer's "portfolio" through school
- know the evaluations, etc. for each consumer
- "train" consumers and families, including specific training on access to systems and agencies, legal issues, etc.
- develop and connect to agency contact opportunities
- focus the consumer on how to select agencies and services vs. doing paperwork
- focus on building relationships among stakeholders
- develop the transition plan with consumers "circle"
- set up trial assessments – "extended shadowing" with an agency

Recommendation 5. Increase Awareness of Opportunities for Students with Developmental Disabilities Leaving High School, Including Current Programs and New or Creative Programs in Development across the County

Goal: Build awareness of choices students may want to consider

Strategies:

- a. Gather information as to current opportunities and resources within Monroe County
- b. Identify target audience—students, teachers, administrators, families
- c. Review current publication “Planning for When the School Bus Doesn’t Stop Here Anymore” for changes and updates
- d. Identify consortium groups and parents for review of School Bus publication and distribution lists for accuracy
- e. Provide enough copies of School Bus publication so that district CSEs could disseminate copies to parents of students who are age 15+
- f. Contact area colleges to develop a strategic plan for increasing pre-service level educators’ knowledge of transition
- g. Work with area parent groups and consortiums to develop agency fairs
- h. Link at school district, NYSED, and BOCES web sites to interrelate in the area of transition

Recommendation 6. Collect and Provide Information on the Individual Needs of Students with Developmental Disabilities Leaving Secondary Education to Allow Effective Planning by Adult Services Providers to Meet the Students’ Needs

Goal: Identify the needs and numbers of students transitioning from secondary school to the adult world

Strategies:

- a. Gather data on student exit needs and outcomes from a variety of adult service agencies including data from individual school districts, DDSO, and VESID
- b. Implement a pilot project to demonstrate effective planning and sharing of information between school districts, OMRDD and adult providers

Recommendation 7. Make it Easier for Students to Access Non-Traditional, Community-Based Programming

Goal: Increase equitable accessibility to existing programs

Strategies:

- a. Identify the variables that affect students' access to community based programming. For example, out of school/agency based programs may not be seen as an approved educational setting, requiring oversight by a certified teacher
- b. Explore ways for school districts to contract with a non-approved school program for the purposes of transition services

Recommendation 8. Increase College-Based Programs for Students with Developmental Disabilities

Goal: Increase alternative and additional educational programs for students with developmental disabilities, to participate in age appropriate learning environments

Strategies:

- a. Conduct outreach to area colleges and universities to facilitate post-secondary opportunities for students with developmental disabilities
- b. Identify and demonstrate successful programs
- c. Identify representatives at area colleges to lead this effort
- d. Work with Pupil Personnel Services (PPS) Directors to demonstrate need and current opportunities
- e. Develop a marketing strategy in collaboration with families on community based instruction for Monroe County
- f. Develop a pilot program with a district, BOCES, and /or a community agency

Recommendation 9. Increase Community-Based Opportunities for Transitioning Students

Goal: Provide more creative opportunities for transitioning students

Strategies:

- a. Identify and demonstrate successful community based programs and/or components of programs
- b. Identify champions with area employers and adult service agencies
- c. Work with PPS Directors to demonstrate need for community based programming and current program opportunities
- d. Develop a marketing strategy in collaboration with families on community based instruction for Monroe County
- e. Develop a pilot program with a district, and/or BOCES and/or an adult agency
- f. Advocate for more flexibility to allow community –based experiences as part of school program

Recommendation 10. Increase School District Compliance with IDEA and SED

Goal: Increase School District Compliance with IDEA and SED

Strategies:

- a. Provide all school districts in the region an opportunity to complete the State Education Department Indicator 13 and 14 self-audit and the Transqual self-audit. These indicators are part of the New York State Performance Plan, which are established to reflect federal regulations. This activity will highlight areas in which the schools are compliant and non-compliant with IDEA and NYSED regulations related to transitioning students. This self- assessment process will result in a clear action plan for the schools to use to become compliant in these areas. Currently, this activity is scheduled to occur over a 6 year schedule for all districts across New York State. We recommend reducing this schedule to a shorter time frame (3 years) to expedite the impact.
- b. Utilize the Transition Coordination Site and SETRC (Special Education Training and Resource Center), which are state education networks located at Monroe County BOCES, to assist in this effort
- c. Seek support for the new schedule from NYSED Regional Representatives
- d. Provide these recommendations to School Superintendents and Directors of PPS

Recommendation 11. Solicit Consumers of School and Adult Services to “Tell Their Stories”

Goal: Increase “real life” information to students and families that will increase their ability to successfully plan and implement transition

Strategies:

- a. Identify adult consumers who have recently exited from area school districts and their families. Ask them to talk about the successes and struggles they experienced in making the transition from school to the adult service system. Provide training and support to enable speakers to tell their stories effectively to all transition constituent groups.
- b. Encourage adult system cooperation in identifying consumers, and preparing the communications with local schools
- c. Utilize Regional Transition Coordination Site to log these stories
- d. Communicate this recommendation to adult provider agencies
- e. Identify consumers to participate in this type of communication
- f. Contact local PPS Directors, High School Principals and Superintendents

Recommendation 12. Increase Access to DDSO Services for Students Who Are OMRDD Eligible

Goal: Increase Access to DDSO Services for Students Who Are OMRDD Eligible

Strategies:

- a. Set up a “Get students qualified” campaign. Roll out information to school administration and staff in the form of how to qualify students for OMRDD services, including service coordination.
- b. Work with adult providers (State and Community agencies) as the experts in training schools in understanding their definition of developmental disability and the documentation required by OMRDD, as well as how to track, appeal and advocate in the process and how to go about selecting an agency and service coordinator.
- c. Communicate campaign to PPS Directors , Superintendents, Greater Rochester Area School Psychologists
- d. Offer training by school district and by regional session

Recommendation 13. Provide Every Student with a Transition Case Manager to be his or her Champion

Goal: Increase the success of person centered transition planning

Strategies:

- a. Provide school districts with a recommendation that every student eligible for transition services be assigned a transition case manager to “champion” that student through their transition from school to life beyond school
- b. Develop training in “Best Practices” with a description of the role and responsibilities of the transition case manager
- c. Create a pilot training program for transition champions
- d. Offer training at school district and regional level. Seek out and support connections between teacher, rehabilitation counseling and social work training programs, and special education programs.
- e. Utilize the Transition Coordination Site and SETRC in the development of Best Practices
- f. Encourage School District investment of staff time for training and function of a transition case manager, to include the philosophy behind person-centered approach
- g. Communicate these recommendations to Superintendents, PPS Directors, and High School Principals

Recommendation 14. Provide All Persons with Developmental Disabilities the Opportunity to Participate in Person-Centered¹⁸ Transition Planning

Goal: Increase the success of person centered transition planning

Strategies:

- a. Develop pre-packaged training programs that will enable each school district to develop staff to lead person-centered planning
- b. Utilize the Transition Coordination Site and SETRC in the development of training with possible collaboration from OMRDD and the Center for Excellence at the University of Rochester

¹⁸ Although person-centered planning has evolved into multiple meanings, essentially, it relates to the consumer at the center of his/her Circle of Support, identifying goals, resources and strategies to achieve these goals through the support of the Circle. There are a wide range of specific and varied person-centered venues for a variety of purposes and occasions. Training is necessary to fully understand and appreciate the effective benefits of these short and long-term approaches.

- c. Encourage school districts to invest staff time for training and work time for participation in person-centered transition planning
- d. Reward/ showcase best practices/ success stories
- e. Communicate recommendation to Superintendents, PPS Directors, and High School Principals
- f. Offer regional training in becoming a person-centered planner

Recommendation 15. Provide Training to Service Coordinators¹⁹ on Transition Planning

Goal: Increase ability of service coordinators to assist with successful transition planning and implementation

Strategies:

- a. Provide training to service coordinators in successful transitions from school to the adult service system. Focus the training to specialize in work with school districts.
- b. Increase collaboration between the Transition Coordination Site and OMRDD in planning training and providing on-going training to accommodate staff turnover
- c. Include training for transition specialists in how to coordinate efforts with service coordinators during the transition years
- d. Communicate this recommendation to OMRDD, Regional Transition Coordination Sites
- e. Develop training module
- f. Schedule periodic training sessions as an orientation of service coordinators

¹⁹ Service coordinators are often unsure of how to work with school districts, and school districts often don't know how to include service coordinators in the planning process, or assume that once a service coordinator is involved their own role is finished.

Recommendation 16. Increase Understanding of Transition Planning and Services by Private School-Age Providers of Students with Developmental Disabilities²⁰

Goal: Provide better transition planning to students with developmental disabilities served by school age providers

Strategies:

- a. Encourage school districts to clearly communicate with private schools who provide services for students with developmental disabilities regarding their expectations for transition planning and services
- b. Work with those private school-age agencies to develop model practices in transitions
- c. Encourage PPS Directors to cooperate with Regional Transition Coordination Site in setting expectations
- d. Encourage heads of private school-age agencies to allow investment of staff time in transition training, planning, service delivery
- e. Encourage PPS Directors to outline expectations of successful transition and communicate those expectations to private school-age agencies

Recommendation 17. Increase Adult Providers' Ability to Plan for New Consumers Leaving Secondary Education Settings

Goal: Adult providers will know how many students with developmental disabilities are coming out of the schools and what their needs are

Strategies:

- a. Provide adult service providers with information on schedule for graduation of students with developmental disabilities
- b. Encourage school districts to complete a form specifying expected graduation dates and service needs upon graduation for students with developmental disabilities
- c. Provide form electronically
- d. Communicate this recommendation to Superintendents and PPS Directors
- e. Involve DDSO in these communications

²⁰ Previously there has been a gap between districts and providers regarding transition, with each making assumptions about who would take responsibility for transition services.

Recommendation 18. Increase Programs and Services Available to Students with Developmental Disabilities Aged 18 to 21

Goal: Provide more options for students with developmental disabilities aged 18 to 21

Strategies:

- a. Encourage school districts to critically review programs and services available for students ages 18-21
- b. Increase school district allocation of staff and resources serving 18-21 year old students with developmental disabilities (See Recommendation No. 4)
- c. Encourage the development of community based education and vocational training programs for students who have “graduated” but are not yet eligible for adult services
- d. Organize a study of 18-21 year old needs through County PPS groups
- e. Analyze study results and develop program service recommendations.
- f. Look at several viable models for community-based instruction for 18-21 year olds currently operating in Monroe County and across New York and Maryland
- g. Communicate these recommendations to Superintendents, PPS Directors, and High School Principals

Recommendation 19. State Agencies Clarify, Monitor and Enforce Roles and Responsibilities of Schools and Adult Services Providers in Providing Transition Services

Goal: Provide more state oversight of transition services provided to students with developmental disabilities

Strategies:

- a. Consumers, family members, school district and agency personnel work with OMRDD and NYSED to clarify the roles and responsibilities associated with transition; and,
- b. Encourage OMRDD and NYSED to provide a clear directive to governmental agencies, school districts and community agencies on the roles and responsibilities of each in the provision of transition services

IX. Steps Forward: Outcomes So Far

The Collaborative Community Transition Planning Process initiated a dialogue that needs to continue. In just over six months of work, we have seen:

- Increased linkages and collaboration between a variety of stakeholders involved in transition
- Increased understanding of the barriers to successful transition
- Efforts by the Finger Lakes DDSO to gather more comprehensive, detailed information on students who recently aged out of the educational system
- Increased discussion within and between school districts regarding the collection of data on transitioning students for planning purposes
- The development of comprehensive recommendations for improving the process which are presented in this report

X. Next Steps

This report is not a final product of the Collaborative Community Transition Planning Process but rather an update to the community. The Steering Committee plans to continue seeking input, developing recommendations and supporting their implementation. We hope each reader will add his or her voice to all these efforts. Working together, we can empower students with developmental disabilities to pursue their hopes and dreams.

The Steering Committee will continue its work in 2007 and invites all interested people to:

- Assist in the implementation of recommendations found in this report
- Develop pilot project proposals that further the work and recommendations of this project
- Guide and monitor efforts to implement recommendations
- Develop and support the implementation of new recommendations

Anyone interested in working with the Collaborative Community Transition Planning Process should contact Allyn Stelljes-Young at stelljes-young@advocacycenter.com.

XI. Conclusion

Throughout this report, we are reminded that students with developmental disabilities want, need and deserve the same opportunities to plan their futures as other students. The laws, systems, practices, personnel and resources support this happening, but much more needs to be done to successfully integrate all the parts involved in transition planning. More creative options are needed to respond to the hopes and dreams of our students.

Let the voices of our youth continue to bring us together and motivate us as we take on these challenges.

- *Don't give up on your dreams.*
- *Don't take no for an answer. Even if people say you can't do something, you think bigger and believe you can do it.*
- *No matter what your disability is, you can achieve it (your goal). Learn what strengths and weaknesses you have and work with them. There are tools and strategies to help.*
- *Don't let your disability be an excuse.*
- *Whatever you choose to do in life, do it for you.*
- *Have confidence in yourself. Follow your heart. You can do it.*
- *Always think the strong way. Think, "I can do it." Live your life to the fullest.*

XII. Appendices

1. Collaborative Community Transition Planning Process
2. Expert Panelists
3. Kick-off Participants

Collaborative Community Transition Planning Process

Mission

The Collaborative Community Transition Planning Process will examine the high school to post-high school transition process, and make recommendations to improve the process and long-term outcomes for students with developmental disabilities and their families.

Process

Preliminary Planning



Kick-Off Breakfast



Steering Committee Convenes



Expert Panels Meet ↓	Research Efforts	Interviews with Key Resources ↙



Steering Committee Reviews Data, Prepares Draft Report including Transition Model and Recommendations



Expert Panels Meet to Provide Feedback on Draft Report



Steering Committee Prepares Final Report and Recommendations



Presentation of Final Report to Community

Expert Panel Participants

Avril Blackwood

Colleen Brown

Sandie Brown-Maynard, Continuing Developmental Services

Terry Chapin, Mary Cariola Children's Center

Deb Clark, Heritage Christian Services

Laura Costa, Spencerport Central School District

Ann Costello, Golisano Foundation

Janet Dreitlein, CP Rochester

Cindy DeFalco, ABVI Goodwill

Ed Dobrowski, Finger Lakes DDSO

Carol Dolan, NYS VESID

Fran Dubester-Vick, Finger Lakes DDSO

Adrian Esposito

Elizabeth Every

Catherine Feely, Catholic Charities

Jennifer Fiorino, Catholic Charities

Bryan Fromm, Epilepsy Foundation

Kay Gebben

Matt Giordano

Marilyn Haile, Rochester City School District

Jean Howard, City of Rochester

Ed Hunt, Rochester Rehabilitation Center

Theo Jordan, Rochester Works

Lynn Keller, Arc of Monroe

Jill Kells-Murphy

Kathy Kerr

Neil Kerr

Dan Lesinski, Hillside

Sharon Marble, Continuing Developmental Services

Lisa McConville, Norman Howard School

Maureen McGory, Ibero-American Action League
Roy Melvin, Boys and Girls Club
Dave Merges, Churchville-Chili Central School District
Sue Mintz, Williamson Central School District
Amy Mitchell, Lifetime Assistance, Inc.
Persephone Modeste, Urban League
Sarah Nettleton
Susan Nettleton
Loren Penman, Byron-Bergen Central School District
Susan Pratt, Monroe 2 BOCES
Mary Pritchard
Jeanne Ricigliano, Midwestern Regional Transition Coordination Site
Barbara Riley, Holley Central School District
Francisco Santiago
Shatara Scriven, Community Place of Greater Rochester
Tom Strining, Webster Central School District
Norann Szczesny
Kathy Terillion
Anne Tutt-Denmark, Community Place of Greater Rochester
Ricky Wright
Ed Yansen, Rochester City School District
Jackie Yingling
Jessica Zegas

Kick-Off Participants

Cherie Bikowsky, Spencerport Schools
Kate Bohne, Office of Senator Joe Robach
Karen Bowlby, Monroe 1 BOCES
Alfreda Brown, EdD, Rochester Institute of Technology
Colleen Brown, The Advocacy Center
Henrene Brown, Urban League of Rochester
Kathryn Cappella, NYS Disabilities Advocacy Association
Shelly Cogliandro, NYS VESID
Laura Costa, Spencerport High School
Ann Costello, Golisano Foundation
Kathy Costello, TIES/Parent
Matt Crowley, AmeriCorps
Linda D'Ambrosia, School of the Holy Childhood
Christin DelGaizo, Churchville-Chili Central School District
Kathleen C. Dillon, Finger Lakes DDSO
Carol Dolan, NYS VESID
Colleen Dox-Griffith, Monroe 2 BOCES
Fran Dubester-Vick, Finger Lakes DDSO
Catherine Feely, Catholic Charities Community Services
Teena Fitzroy, Monroe 1 BOCES
Bryan Fromm, Epilepsy Foundation
Nyla Gaylord, Rochester Rehabilitation Center
Kathleen M. Graham, Arc of Monroe
Marie Greer, Mary Cariola Children's Center
Diane Gyle, School of the Holy Childhood
Marilyn Haile, Rochester City School District
Susan Hetherinton, University of Rochester/ Warner School
Ed Hunt, Rochester Rehabilitation Center
Michael Johnson, Monroe Community College/ Damon City Campus
Shelia Jones, Urban League of Rochester

Lynn Keller, Arc of Monroe
Brian Klafehn, CP Rochester
Carol Kramer, NYS VESID
Patricia Krueger, Rochester City School District
Anne E. Kurz, Wegmans Food Markets, Inc.
Kay Kurz, Dedicated Mother
Patty Larke, Office of Congresswoman Louise Slaughter
Kathy Leahy, St. Joseph's Villa
Dan Lesinski, Hillside Children's Center
Morris Lew, Continuing Developmental Services/Unistel
Dwayne Mahoney, Boys and Girls Clubs of Rochester
Nichole Malec, Office of Assembly Member Susan John
Maureen McGory, Ibero-American Action League
Audrey McNally, Brighton Central School District
Lynn Mellas, Gates Chili High School
Dave Merges, Churchville-Chili Central School District
Yvette Mirabal, CP Rochester
Amy Mitchell, Lifetime Assistance Inc.
Martha Mock, University of Rochester / Warner School
Persephone Modeste, Urban League of Rochester
Jim Mroczek, Arc of Monroe
Jennifer Muller, Monroe 1 BOCES
Sara Nettleton, Student
Susie Nettleton, Parent to Parent of NYS
Gail Nofziger, Parent
Marie O'Horo, Finger Lakes DDSO
Sue Ormandy, Lifetime Assistance Inc.
Anne O. Sawyko, Catholic Charities Community Services
Joan Parker, Heritage Christian Services
Rebecca Payton, Regional Center for Independent Living
Mary Pritchard, Spina Bifida Association

Rene Reese, Rochester Works
Jeanne Ricigliano, Midwestern Regional Transition Coordination Site
Barbara Riley, Holley Central School District
Susan Rizzo, Monroe 2 BOCES
Gaie Sarley, Monroe 2 BOCES
Ann L. Scherff, The Advocacy Center
Paul Scott, Mary Cariola Children's Center
Kim Segal, LDA Life and Learning Services
Sankar Sewnauth, Continuing Developmental Services
Paul Shew, The Advocacy Center
Amy Silber, Learning Disabilities Association
Erin Sperry, Transition Site - WFL Region
Allyn Stelljes-Young, The Advocacy Center
Norann Szczesny, The Advocacy Center
Anne Tutt-Denmark, Community Place of Greater Rochester
Janet VanZile, Monroe 2 BOCES
Josara Wallber, NTID at Rochester Institute of Technology
Julie White, Monroe Community College / Damon City Campus
Arlene Wilson, Center for Disability Rights
Jackie Yingling, The Advocacy Center
Ray Yingling, Parent
Therese Zona, Midwestern Regional Transition Coordination Site
Lyn Zyla, Self-Advocacy Association of NYS, Inc.