Minnesota Follow-up Study: What Happens to Young Adults with Disabilities after High School?

Concern about what happens to youth with disabilities once they leave high school has been a national priority for the past several years. Interviews with 388 young adults with disabilities throughout Minnesota were conducted in the summer of 1993, and the results were recently published in the 1994 Minnesota Post-school Follow-up Study, by the Institute on Community Integration, University of Minnesota, under contract with the Interagency Office on Transition Services, Minnesota Department of Education.

The study was conducted in the following communities: Albert Lea, Duluth, Hopkins, Minneapolis, New Prague, Rochester, St. Cloud, Thief River Falls, Willmar, and Windom. The former students interviewed had left high school between 1988 and 1992, and had been diagnosed with a primary disability in the following categories: learning disability (N=148); emotional/behavioral disorder (N=55); mild mental impairment (N=95), and moderate/severe disability (N=90). Ninety-two percent of the individuals interviewed were high school graduates. Major findings of the study included:

Employment: Eighty percent of the young adults were employed; 50 percent in competitive jobs, 13 percent in supported employment, and 16 percent in sheltered employment. Among the 20 percent who were unemployed at the time of the interview, only 9 percent had never been employed. Those working in competitive jobs found work through personal contacts (i.e., self/family/friend networks). Supported employment services were used primarily by youth in the mild mentally impaired and moderate/severe disability groups. A much larger percentage of young adults in the moderate/severe disability group (56 percent) worked in sheltered employment settings in comparison to the other groups.

Postsecondary Education and Training: Nineteen percent of the respondents (mostly individuals with learning disabilities) were enrolled in, or had completed, technical college, community college, or university/four year college, or an apprenticeship. However, most of the remaining respondents had never considered enrollment in postsecondary education and training programs.

Living Arrangements: Most young adults (62 percent) lived in their family homes, and very few participated in programs that prepare individuals to live on their own. Forty-one percent were on a waiting list for somewhere else to live.

Social Networks: Nearly two-thirds (66 percent) of the sample had social networks ranging from three to eight people. Young adults in the moderate/severe disability group had the fewest number of personal friends in their social networks, but included more staff and professionals.

Recreation and Leisure Activities: "Watching TV/listening to music" and "going out to eat" were the two most popular recreation/leisure activities. Young adults with learning disabilities were more likely to spend their free time engaged in social activities than others in the sample.

Community Participation and Citizenship: Most of the individuals with learning disabilities and those with emotional/behavioral disorders drove a car or took public transportation. Young adults with learning disabilities were more likely to serve on committees, have a job, or be a member of religious organizations than others in the sample.

FY 1995 Cost of Care Rate at RTCs Announced

The Minnesota Department of Human Services (DHS) recently announced the daily rates for the Cost of Care in Regional Treatment Centers (RTCs) for persons with mental retardation and related conditions. Effective July 1, 1994, the daily charge for care for each person at the seven RTCs will be $324 per day, or $115,344 per year. This is only a slight increase from last year's rate of $310 per day; $113,150 per year. DHS calculates interim charges on a per diem basis for each fiscal year by dividing the sum of all anticipated costs by the projected resident days.

As of June 1994, the total population of persons with mental retardation and related conditions residing in all seven RTCs was 702. RTC populations have decreased consistently over the past years: 862 residents in 1993; 1,033 residents in 1992; and 3,065 residents in 1977 (or, a reduction of 77 percent over the past 17 years).

For more information, contact Larry Houff, Reimbursement Division, Department of Human Services Building, 444 Lafayette Road, St. Paul, MN 55155-3824. 612/296-4889.

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- Leadership Institute Held in Minneapolis
- Cost-Effective Personal Assistance Services

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The following resources are available on loan: publications for three weeks; videotapes (VHS 1/2" cassette) for two weeks. The only cost to the borrower is the return postage.

Publications:
How to Get Services by Being Assertive: For Parents of Children with Disabilities and Their Helpers (Revised 1993), Charlotte Des Jardins, Family Resource Center on Disabilities, Chicago, Illinois. Provides a process toward empowerment for parents and persons with disabilities. The authors state, "If you're not satisfied with your quest for services; if you're tired of all those 'nos' and 'can'ts'; and if you really want to do something about it---this book is for you." How to Organize an Effective Parent/Advocacy Group and Move Bureaucracies (1993), C. Des Jardins, Family Resource Center on Disabilities, Chicago, Illinois. This is a comprehensive guide for starting and maintaining effective parent and/or advocacy organizations—including how to: reach out to other parents, recruit volunteers, raise money, influence policies, keep an organization healthy, and, most importantly how parents can help their children and themselves by joining forces with others. Developing Natural Supports in the Workplace (1993), Center on Human Policy, Syracuse University. Results are shared from a project about how to foster social relationships in integrated work settings during typical routines and activities. Provides helpful checklist for evaluating natural supports.

Cost-Effective Plan Recommended for Personal Assistance Services

The World Institute on Disability (WID) has released the results of a study of the cost of personal assistance services (PAS) that has major implications for lowering the estimated cost of the PAS portion of the Clinton Health Reform Bill. Results of WID's study, revealed that the cost per hour of service can be reduced by one half if individual providers administer the service (e.g., hiring, firing, training, and paying the assistant) rather than having them organized through a home health care agency.

Personal Assistance Services (PAS) are tasks performed for a person who has a disability by another person which aim at maintaining well-being, personal appearance, comfort, safety, and interactions within the community and society as a whole. Between 9 and 11 million Americans, about one in every 20 people, require some assistance to accomplish typical every-day tasks.

On the average, agency providers cost nearly twice as much as individual providers (that is, a mean average of $10.20 vs. $5.25, per hour respectively). More than half of this difference is not the result of paying individual providers less, but reflects the administrative and bureaucratic costs built into the big business of home health care. "Savings to the entire system which might be realized under individual provider models are so substantial that no policy discussions can afford to ignore them," concluded Ed Roberts, WID president. Roberts continued, "Long-term assistance proposals are traditionally weighted heavily toward home health agency services. But, if individual providers were substituted in many instances, twice as many people could be served for the same price. It is in everyone's best interest to offer 'the choice model,' which offers both greater support for independent living and lower costs," Roberts concluded.

Publicly funded PAS programs currently serve about 11 percent of people who need assistance. Another 10 percent pay for services out of pocket. The remainder receive only unpaid assistance from family and friends. Some even struggle along without assistance and some remain in institutions, such as nursing homes, for lack of adequate assistance to live in the community.

For more information, contact: World Institute on Disability, 510 Sixteenth Street, Suite 100, Oakland, CA 94612-1500. 510/763-4100 (voice & TDD), 510/763-4109 (fax).
Inclusive Education: Assessing Needs of Families in Minnesota

"Many parents who have school-age children and youth with disabilities, by virtue of the barriers they face, do not always have a full choice of where or how their child should be educated. In addition to facing the barriers related to a disability, children also appear to be segregated by economic, ethnic, and age criteria." This was the major conclusion reached in a recent survey of Minnesota parents.

The Family Needs Assessment arose out of an identified need in Minnesota to evaluate the experience and needs of families relative to the inclusion of children with disabilities in general education. The survey and report were produced by the Together We're Better Program: Inclusive School Community, a collaborative program between the Institute on Community Integration at the University of Minnesota and the Minnesota Department of Education. The study was also conducted in partnership with PACER Center, Arc Minnesota, The Governor’s Planning Council on Developmental Disabilities, Learning Disabilities of Minnesota, and the Deaf-Blind Technical Assistance Project. Parents, advocates, educators, and persons with disabilities all played a role in the development of the survey.

Approximately 6,500 questionnaires were distributed, and 1,630 (25 percent) parents responded. The study sample was representative of Minnesota’s population (with 50 percent of the families living in the Twin City metropolitan area), and the population distribution by type of disability. However, one way in which the study sample differed from the state population was that many parents were from school districts that had demonstrated leadership and progress in the development of inclusive school communities, had received training on inclusion-related advocacy, or had been involved with parent groups supporting inclusion. As a result of these supports, the rate of inclusion for children in this study may be higher than would be typical across the state.

Major findings of the study are summarized in the following categories: educational placement, parent satisfaction, inclusion of students in general education, and parent support.

Educational Placement

Where are students with disabilities being educated?

Projecting from this survey, of all the children receiving special education in Minnesota, probably:

- Less than 25 percent are being served solely in general education classrooms.
- More than 50 percent are being served in a combination of special and general education settings.
- At least 20 percent are totally segregated in special education environments.

Note: Parents of children in mixed environments were least satisfied with their child’s progress, yet this is how most children received services.

Where do parents want their children to be educated?

- Ninety-four percent want their child to spend at least some time in a general education setting.

Council Seeks New Members

Applications are being accepted for serving on the Minnesota Governor’s Planning Council on Developmental Disabilities. Those appointed by the Governor will begin serving on the Council for a three-year term in early 1995.

The Council assists in the section of priorities for the development of a state plan. The Council also advises state policymakers on issues pertaining to the provision of an array of services to individuals with developmental disabilities and their families, such as in the area of health, education, human services, housing, and transportation.

Individuals with "developmental disabilities" are those who have severe, physical or mental disabilities which occur before age twenty-two and are likely to continue indefinitely. A developmental disability significantly limits three or more major life activities such as: self-care, language, learning, mobility, self-direction, independent living, and economic self-sufficiency.

Individuals who have a developmental disability, parents, and providers of services are encouraged to apply. Applications are due by January 1, 1995.

Please contact the Office of the Secretary of State to request the form entitled "Application for Service in State Agency." Address: Secretary of State, 180 Constitution Avenue, St. Paul, MN 55155. Telephone: 612/296-3266.
Division of Family Health Created
The Minnesota Department of Health recently announced that effective August 24, 1994, the Division of Maternal and Child Health and Sections from the Division of Health Promotion and Education will merge to form a new Division: Division of Family Health. Director of the Division is Donna Petersen. 612/623-5167.

Public Input Requested on Education of Students with Disabilities
The Task Force on the Education of Children with Disabilities was reappointed by the 1994 Legislature to make recommendations related to four issues: 1) entrance-exit criteria; 2) homebound education and related issues; 3) class size/teacher-pupil ratios; and 4) the development of a technology plan for special education. The Task Force is seeking oral feedback or statements in writing regarding these specific issues. What should be kept, changed, or eliminated? What is good? What problems have you experienced? Responses must be made no later than October 30, 1994. Contact: Patty Anderson, 8th Floor Capitol Square Building, 550 Cedar Street, St. Paul, MN 55101. 612/296-6104.

Examples of Interagency Collaboration/Transition Services Requested
The Minnesota Department of Education, Division of Rehabilitation Services, and State Services for the Blind are currently working together to describe and clarify the joint provision of services to youth with disabilities from school to work and community living. A guidebook will be published which will share how agencies have collaborated through use of state and federal legislation, policies, funding sources, and examples of coordinating services to individuals. Stories are also needed on how individuals are provided with supports and services. Contact: Teri Wallace, Institute on Community Integration, 6 Pattee Hall, University of Minnesota, 150 Pillsbury Drive, SE, Minneapolis, MN 55455. 612/626-7220 (voice); 612/624-9344 (fax).

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- The majority wanted their child to spend most of their time in a general education setting.
- One third wanted their child to spend most of their time in a special education setting.

Note: Parents whose children spent more time in general education felt stronger about having their child included in general education.

What influences whether a student spends most of his/her time in general education settings?
- Parent preference: If the parent wants their child in general education, that is where they tend to be educated.
- Severity of a child's disability: The more severe the disability, the less likely the child will be educated in general education.
- Age: Children tend to spend more time in general education during the elementary years and much less time in general education at the preschool, middle school, or high school levels.

Parent Satisfaction
What needs to happen to ensure parent satisfaction with their individual educational planning process (IEP)/individual family service plan (IFSP) experience and with their child's progress?
- Believe that my child can learn and be optimistic in setting goals.
- Respect and value my input and feelings.
- Don't forget to develop social and behavioral goals.
- Help all children value and treat one another well.
- Train all staff to understand the content and goals of the individual educational planning process (IEP).

Which parents tend to be least satisfied with their child's progress?
- Parents with a high school age child.
- Parents whose child has a severe disability.
- Parents whose child has an emotional behavioral disability.
- Parents of color.
- Parents with low incomes.
- Parents who are single.

Note: 1) Parents of color and families with low incomes were not only less satisfied with their child's progress, they also received less information and support, and their children were disproportionately placed in special education, particularly in the category of emotional behavioral disabilities; 2) When parents of color had the support of an advocate, their positive experience with the IEP process, overall satisfaction, agreement that their child benefited from being in general education, and the desire to have their child in general education increased to 100 percent on all measures for most ethnic groups. The support of an advocate had a similar effect with low income families.

Inclusion of Students in General Education
What worries parents about having their child educated in general education settings?
- Will my child get the support they need?
- Will they receive good instruction?
- Will other children accept my child?
- Will my child learn?

What did parents identify as barriers to successful school inclusion?
- Lack of money in schools.
- Large class sizes.
- Lack of skill by general educators in working with students with disabilities, and particularly in working with behavioral issues.
- Attitudes of other students toward students with disabilities.
- Members of a child's team not working well together.

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- Attitudes of general educators toward students with disabilities.
- Rigid or narrowly defined instructional goals in general education, and, in particular, goals for their child.
- Teaching methods used in general education.
- At the secondary level, grading practices.
- Racial insensitivity (as identified by African American, Asian, and Latino parents).

Note: Parent concerns decreased when students spent more time in general education. As an example, related to how their child will be participating or del¢

Education. As an example, related to how their child will be participating or del¢

Integration, University of Minnesota, St. Paul.

In August 1994, focus group training was provided for representatives of the program and with parents and staff in their classrooms. _

Steps _

For more information about the survey results or focus group opportunities, please contact the Institute on Community Integration, 111 Pattee Hall, 150 Pillsbury Drive, SE, Minneapolis, MN 55455. 612/624-1349. Copies of the full report or a thirteenth page executive summary, Inclusive Education: Needs of Minnesota Families, 1994, (available in print and alternative formats) can be ordered by contacting the Publications Office, Institute on Community Integration, University of Minnesota, 109 Pillsbury Drive, SE, Minneapolis, MN 55455. 612/624-4512.

Events


November 8, 1994: "Pre-Conference Workshop on Early Intervention (Part II)" Mall of America Grand Hotel. Contact: Pam Hunt, Institute on Community Integration, University of Minnesota, Pattee Hall, 150 Pillsbury Drive, NE, Minneapolis, MN 55455. 612/625-3863.

November 9, 1994: "Coming Together for Children, Youth, and Families," a collaborative conference for members of: Interagency Early Intervention Committees, Local Coordinating Councils, Local Advisory Councils, and Community Transition Interagency Committees. Location: Mall of America Grand Hotel, Bloomington, MN. Contact: Pam Hunt, Institute on Community Integration, University of Minnesota, Pattee Hall, 150 Pillsbury Drive, NE, Minneapolis, MN 55455. 612/625-3863.

November 21, 1994 (12:00 noon to 4:00 p.m.): Ninth Annual Job Success Fair, "Exploring Your Options," Marriott Hotel-Bloomington, is for individuals with disabilities. Contact: Nancy K. Schuett, City of Bloomington, 612/881-5811 (voice); 612/887-9677 (TDD).

Lending Library

The following resources are available on loan; publications for three weeks; videotapes (VHS 1/2" cassette) for two weeks. The only cost to the borrower is the return postage.

You Can Vote, videotape, 30 minutes, Michigan League of Women Voters and Michigan Developmental Disabilities Council, encourages people with disabilities to meet their responsibilities as citizens—to register, and to vote.

Kids Belong Together, videotape, 30 minutes, People First Association of Lethbridge, Alberta, Canada. Through cohesive circles of friends, communities become a place for everyone. Parents and children with disabilities learn the importance of dreaming for the future and to share these dreams with others. Scenes primarily in elementary school settings.

Our Voices Count: Self Advocacy Now, Self Advocacy Association of New York State, Inc., People with disabilities speak out, encouraging others to voice their concerns, as well.

No lasting achievement is possible without a vision, and no dream can become real without action and responsibility.

William Butler Yeats

DRAganet Expands Computer Services

DRAganet, a Minnesota-based nonprofit group serving people with disabilities, has relocated its office to the historic Textile Building in downtown Minneapolis. The move accompanies an expansion of the DRAganet RE=PC computer recycling project which provides low-cost access to computer technology for disadvantaged individuals and the nonprofit service community.

RE=PC offers a tax-deductible donation for computer equipment. The donated equipment is then refurbished and placed with people who would not otherwise be able to afford similar equipment. The project generates high technology skills training and employment opportunities for people with disabilities. Another service, Computer Precision, provides fee-based consulting to organizations, and provides system design, management and training.

In addition, DRAganet Information Service, an electronic bulletin board, provides worldwide information on disability related topics, which can be reached with a computer and modem at 612/753-1943 (ANSI emulation; eight data bits, no parity, and one stop bit [8-N-1]). This newsletter, Futurity, is available via the DRAganet Information Service.

For more information, contact: DRAganet, 119 North Fourth Street, Suite 405 Textile Building, Minneapolis, MN 55401. 612/338-2535.

Council Publications in Alternative Formats:

1) Friends: A Manual for Connecting Persons with Disabilities and Community Members, Human Services Research and Development Center, on audio cassette;
2) Futurity, on audio cassette and is available through DRAganet and Children, Youth, and Family Consortium Clearinghouse (electronic bulletin boards);
3) Making Your Case, Braille, computer disk, and audiotape;
4) Minnesotans Speak Out, Summary of Town Meetings, audio cassette;
5) Shifting Patterns, publication in Braille and on audio cassette; and videotape with closed captions;
6) It's Never Too Early, It's Never Too Late videotape, is available with closed captions; and
7) It's Never Too Early, It's Never Too Late publication, is available on audio cassette.

See return address and telephone numbers, below.

On Wednesday, October 5, 1994, the United States Senate adopted the Conference Committee Report to reauthorize the Elementary and Secondary Education Act (ESEA). Section 315 of this Act contains the "Families of Children with Disabilities Support Act of 1994." According to Allan Bergman, director of State-Federal Relations of United Cerebral Palsy Associations, as of October 7, 1994, this new legislation was on its way to President Clinton for his signature.

The legislation is the result of much hard work by individuals and organizations throughout the country. "Our jointly developed values, principles, and policies for family support are about to become the law of the land!" exclaimed Bergman. [See previous article: "National Family Support Legislation Drafted," Futurity (July 1993)].

"Unfortunately," continued Bergman, "because of the extensive delay in bringing ESEA to a vote, funding was not secured under the new federal budget which began on October 1, 1994. Bergman said that this new legislation will establish a new foundation for the reauthorization of Individuals with Disabilities Education Act (IDEA) next year. "We will have to work diligently with the members of the Senate and House Labor, Health and Human Services and Education Appropriation Subcommittees next year to secure appropriations for the federal fiscal year beginning on October 1, 1995."

According to Senator Tom Harkin, Chair of the Subcommittee on Disability Policy, Committee on Labor and Human Resources, "It is now the policy of the United States that (quoting directly from the legislation):
(1) Family support for families of children with disabilities must focus on the needs of the entire family.
(2) Families of children with disabilities should be supported in determining their needs and in making decisions concerning necessary, desirable, and appropriate services.
(3) Families should play decisionmaking roles in policies and programs that affect their lives of such families.
(4) Family needs change over time and family support for families of children with disabilities must offer options that are flexible and responsive to the unique needs and strengths and cultural values of individual families.
(5) Family support for families of children with disabilities is proactive and not solely in response to a crisis.
(6) Families must be supported in their efforts to promote the integration and inclusion of their children with disabilities into all aspects of community life.
(7) Family support for families of children with disabilities should promote the use of existing social networks, strengthen natural sources of support, and help build connections to existing community resources and services.
(8) Youth with disabilities should be involved in decisionmaking about their own lives, consistent with the unique strengths, resources, priorities, concerns, abilities, and capabilities of each such youth.
(9) Services and supports must be provided in a manner that demonstrates

Family Support Act continued on page two
Competence continued from page one

What people really need to understand is that they are only temporarily able-bodied and that we are all a part, in and out, of our respective communities. People are only a drunk driver or a bar of soap away from having a disability. What all of us need is to be fully competent, fully able to do the very best of our abilities what we want to and need to do in our communities and our work places.

Discrimination is alive and well everywhere you look:

- Most discrimination is annoying, and is usually not intentional.
- Most discrimination is on an unconscious basis—you need to go deep to find it.
- You know you are being discriminated against when you can’t get the services you need, while others are getting the services they need.
- You know you are being discriminated against when you’re the only one in the room like yourself.

When thinking about services and cultural competency, we need to be planful.

Progress does not happen overnight. Nor can we expect to accomplish our tasks in three months, or three years, and be done.

Diversity is more complex than that. We need to plan for a long-term commitment, beyond the usual three-year cycle that is doomed to fail.

When planning, we need to allow for the mistakes we will inevitably make. Mistakes do happen, and we need time to recover from them. Taking risks is what it’s all about. However, don’t make the same mistakes twice. Be planful for change—change that is long-term.

Utilize your connections, or networks in the community, and be willing to pay for people’s assistance. Parents, in particular, from diverse cultural backgrounds, are worn out from having to train the traditional white professional to do their jobs. Even if they offer to do a job for nothing, make an offer to pay for their services.

Minnesota has many challenges in an increasingly diverse society. We are the pioneers in the area of dealing with diversity, and we must work thoughtfully, planfully, in a relationship with a community that is long-term.

[Vivian Jenkins Nelsen is president and chief executive officer of INTER-RACE, located on the Augsburg College campus. This article is a summary of her recent presentation to the Council on Developmental Disabilities.]

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respect for individual dignity, personal responsibility, self-determination, personal preferences, and cultural differences of families.

The primary purpose of the Act is "to provide financial assistance to the states to support systems change activities designed to assist states to develop and implement, or expand and enhance, a family-centered and family-directed, culturally competent, community-centered, comprehensive, statewide system of family support for families of children with disabilities. Grants to states will be on a competitive basis to support systems change activities to develop and implement, or expand and enhance, a statewide system of family support for families of children with disabilities."

Other features of the Act include:

- Grants to States: Grants will be awarded on a competitive basis for no more than three years.
- Lead Entity: The Chief Executive Officer of a state shall designate the office, or lead entity, to administer and coordinate the activities under the Act.
- State Policy Council: Before receiving funds, the state must designate an existing Council, or establish a new Council, to be considered as a "State Policy Council for Families of Children with Disabilities." Such Councils must consist of a majority of members who are individuals who are family members of children with disabilities, appointed by the Chief Executive Officer of the state or the appropriate appointing official. Additional representation must include: children with disabilities, who are ages 18 to 21 and are representative of the demographics of the state; state agency representatives; state officials responsible for budget and finance; and others deemed appropriate.

Authorized Activities: A state that receives a systems change grant may use funds to:

- Provide training and technical assistance for family members, service providers, community members, professionals, members of the Council, students, and others to accomplish: increase family participation, choice, and control of family support; promote partnerships with families; develop or strengthen family-centered and family-directed approaches; assist families in accessing natural and community supports, and in obtaining benefits and services;
- Provide interagency coordination of federal and state policies, resources, and services;
- Enhance funding options and coordinate access to funding for family support services;
- Document and disseminate information about interagency activities;
- Develop local and regional councils;
- Conduct outreach activities to locate families who are eligible for family support;
- Support policy studies;
- Conduct hearings, forums, and needs assessments;
- Conduct public awareness and education activities; and
- Support pilot demonstration projects.

Strategic Plan: Not later than 6 months after receipt of funds, the lead entity (office) in conjunction with the Council, shall prepare and submit a strategic plan to the Secretary of Health and Human Services. The plan will spell out the mission, principles, goals, and objectives for developing and implementing, or expanding and improving, the system for providing family support services for families of children with disabilities, and the achievement of family-centered outcomes.

For more information, contact: Allan J. Bergman, State-Federal Relations, United Cerebral Palsy Associations, 1522 K Street, NW, Suite 1112, Washington, DC 20005-1202. 800/USA-SUCP; 202/842-1266 (voice and TT); 202/842-3519 (fax).
Getting a Life
(Part One of a Two-Part Series)
by Ann Turnbull

I want to tell you our family story. When Jay was finishing high school, about eight years ago, there was a new thing called supported work, a real job, rather than students with disabilities going to a sheltered workshop or just graduating to unemployment. When we mentioned supported employment for Jay to his teacher, she thought we were being unrealistic, that we still hadn't accepted the extent of his disability (mental retardation and autism), and that we really needed to get in touch with the fact that he was the lowest functioning student in the class. She said that all the students much more capable than he were going to a sheltered workshop. Why did we think he should get special treatment? My husband Rud and I said that we didn't think he should get special treatment, they should all go to supportive work! But that wasn't the vision for people with severe disabilities.

Jay now has a wonderful life, and I think you will agree that if he can have a wonderful life in Lawrence, Kansas, then people can have a wonderful life anywhere. But it takes a different way of thinking and the fundamental thing is, you have to get off the back of the bus. You have to refuse to be a second-class citizen. You have to live in the world the way you would if the disability wasn't there. That's a whole different way of delivering services, of providing supports, and for families to live.

Well, Jay was in high school. He had gone, as all the special education students did, on this escalator to the sheltered workshop, where he was earning about fifty cents an hour. He was very unhappy and very depressed. He didn't have a language to say I hate my life, I feel like a second-class citizen, I don't really like living in the herd mentality of 22 people going everywhere together in the community. Not having the words to say those things, he acted out in behavior what he wasn't able to say in words. When people have severe behavior problems, it's a form of communication. They're saying "I'm unhappy, I feel trapped, I don't like my life." So, Jay started hitting and choking people, he started pulling the curtains off the wall in the group home and ripping up the mattress. Our phone was ringing all the time with the latest behavioral problem. He chose one person to hit and choke every time he saw him, and wouldn't you know, it was the state senator's son. I don't know if Jay understood the full significance of how quickly that was going to get him kicked out of this program. He soon got a one-way ticket out.

So, at nineteen Jay was kicked out of the only program in town and he really didn't have friends. Think about the people with severe disabilities you know and how many connected, reciprocal friendships do they have? That's one of the things that we've overlooked in the field of disability. You know why? We thought it was unrealistic. You know what? It's not unrealistic! But it doesn't happen because we have it in our minds that our answers lie in our formal services and the family support, not necessarily in the ordinary citizens in the ordinary places in the community who have a tremendous capacity to reach out and provide support. But they think it's not their role because this whole formal system is set up to do that.

About that time in our lives, we took a sabbatical and moved to Washington, D.C. We were fortunate to find a wonderful high school program for Jay to attend when he was 21, his last year of public school eligibility. Within a couple of weeks, Jay was beginning to react in a very different way. Jay had a very hip, groovy, cool teacher who believed that he could ride in the front of the bus. Within the first week it was her idea that he should be football manager, an idea that had never occurred to us! Jay gave towels out, and with his autistic characteristics, every player had a towel whether he needed or wanted one or not! He was the first giver-out of towels that they had ever had on the team! So, after a few games, they started inviting him into the dressing room at half-time and with them for their away games. They started inviting him to ride the bus. Do you know how that changes a person who's always been on the fringe of everything?

I will never forget the night that Jay and his dad and I were at the football banquet at the Walt Whitman High School in Bethesda, Maryland. The coach was up in front. He gave letters to the cheerleaders and then started talking about the manager and called Jay up front. He didn't say one word about disability, Special Olympics, special tutoring—none of the language or the baggage of disability.

He said that Jay had just been here for a year. He's been a great manager, we wish he wasn't graduating, and we have this football jacket for him. Jay was beaming. That night, I think, was a turning point in our lives. We saw that we didn't have to always live on the fringe, that Jay really could participate.

[This article is from a presentation made by Ann Turnbull at West Virginia's Early Intervention Summer Conference (1994). Ann and her husband, Rud, direct the Beech Center on Families and Disability at the University of Kansas. Special thanks are extended to Ann Turnbull and The Arc of Harrison County, Clarksburg, West Virginia, for permission to reproduce this article from Fair Shake, Quarterly Magazine of West Virginia's Fair Shake Partnership (Fall 1994). Part 2 will appear in the December issue of Futurity.]

Events


Multimedia Expands Training Opportunities

Through broader availability of personal computers and the emergence of multimedia, opportunities for training more people at greater distances are becoming increasingly available. According to CityBusiness, (September 9, 1994) "a host of Twin Cities firms are making multimedia a core part of their business, as advertising agencies, graphic design firms, film and video production houses, and training firms embrace the power of multimedia.

"When we got involved with multimedia five years ago," said Fred Badiyan, founder and president of Badiyan Productions, Inc., in Bloomington, "there was no name for it then. Now it's a very hot thing." He continued, "There was a time when film was a film, video was a video, slide was a slide, and the computer was known for text. Now all of those common tools are merging. When they merge, it's called multimedia."

It doesn't take a multimillion-dollar company to make it in the multimedia world. In some ways, multimedia production today can be likened to the nascent desktop publishing world of the mid-1980s--a field in which pioneers contract out their services to larger clients that don't have the expertise or commitment to the field.

Jane Wells of Interactive Learning Technologies in White Bear Lake is one such pioneer. She's developed multimedia presentations for Learning Disabilities of Minnesota and the Minnesota Governor's Planning Council on Developmental Disabilities.

"I remember when I decided to get into the multimedia field: Inauguration Day 1993, when I was caught in an ice storm near Redwood Falls on my way to do some training," Wells said. "I realized that technology makes other things possible, and I love computers, so I figured there were other ways to get information to people, taking advantage of technology, without risking my neck in an ice storm." That led to an investment in multimedia authoring tools and a shingle proclaiming her status as a "content professional," as she puts it.

"There's a real disparity in terms of access across the state," Wells said. "In the Twin Cities, you can get lots of training. If you live in Thief River Falls or Crookston, you need to drive to the Twin Cities to get the good stuff, especially in human services."

"Use of multimedia is a way for everyone to hear everything at the same time."
Interfering with Choice

I think that those of us who feel that a choice is a right make a mistake when we let people frame the issues around extreme hypothetical situations that happen once every ten years. The truth is that most of the interference with choice actually occurs in much more mundane, routine non-crisis kinds of matters. Things like when we eat, when we're allowed to use the telephone, who we can associate with, what we do with our time. That's where most of us have felt the most intruded upon and where the lack of choice has really been a burden to us over a period of years.

Darby Penney
Recipient Affairs, New York State Office of Mental Health

Correction: "Council Seeks New Members," (October 1994)
The article requesting applications for membership to the Governor's Planning Council on Developmental Disabilities in the October issue of *Futurity* listed incorrect information. The correct information is: Interested applicants should contact the Governor's Office. Request the form, "Open Appointments Application for Service on State Agency." Applications are due January 1, 1995.
Contact: Cheryl Talberg, Governor's Office, 130 State Capitol Building, 75 Constitution Avenue, St. Paul, MN 55155. 612/296-0077 (voice/Metro Area); 800/657-3598 (voice/toll-free); and 612/296-0075 (TDD).

Inside This Issue...
- "Getting a Life" by Ann Turnbull (Part Two--Conclusion)
- Federal Grant Expands Respite Care to Families

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Home and Community-Based Services Waiver Program Expanded

Assistant Commissioner Helen Yates, Minnesota Department of Human Services, recently announced that the Health Care Financing Administration has approved an amendment to the state’s waiver program for persons with developmental disabilities and their families. The amendment will significantly revise the menu of services and supports available to participants. Submitted in May 1994, this amendment adds coverage of the following services to the state’s primary Home and Community-Based services waiver program for individuals with developmental disabilities:

- (a) 24-hour emergency assistance;
- (b) specialist services;
- (c) caregiver training and education;
- (d) adult day care;
- (e) housing access coordination;
- (f) assistive technology;
- (g) personal support;
- (h) environmental modifications (replacing the service titled "adaptive modifications and equipment");
- (i) in-home family support (revising the definition to include extended family members); and
- (j) homemaker (which revises provider qualifications).

"These services will expand the options of services available and better meet individual needs," said Yates.

For additional information, contact your local county case manager or call the "Policy Line" of the Minnesota Department of Human Services: 612/296-9747.

[Source: DHS *Information Bulletin*, in press.]

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Minnesota Develops National Employment Model for People with HIV/AIDS Disabilities

Commissioner R. Jane Brown of the Minnesota Department of Economic Security recently announced that Minnesota has received a grant from Special Education and Rehabilitative Services, U.S. Department of Education, to conduct a national pilot program. The $900,000 program will emphasize the employability of people with HIV/AIDS. Over 1,200 rehabilitation counselors in Minnesota and five other states will receive training under the project. Under the grant, Minnesota Department of Economic Security will join forces with the World Institute on Disability, California, Colorado, Florida, New York, and New Jersey.

"Because of advancements in medical technology, people with the HIV/AIDS virus can live for years, and can continue to lead productive lives," said Norena Hale, director of the Division of Rehabilitation Services. "When working, people with the HIV/AIDS virus tend to feel better and do not need as many medical services," she added.

As of August 1994, there were 2,196 Minnesotans reported to have AIDS, of whom 88 percent lived in the seven county metropolitan area.

For more information, contact: Allan Lunz, Minnesota Department of Economic Security, 390 North Robert Street, St. Paul, MN 55101. 612/297-1596.
Arc Program Provides Incentives to Employers
The Arc has a established an On the Job Training (OJT) program with funds from the United States Department of Labor. Funds are provided to service providers for reimbursing employers for providing job opportunities to persons with mental retardation. Employers may be reimbursed for 50 percent of the employee's entry wage for the first 160 hours. Contact: The Arc, National Employment and Training Program, 800/433-5255 (voice); TDD users, call 800/855-1155 and ask to place a collect call to 817/277-0553.

Volunteers Wanted
Chrysalis, A Center for Women, is looking for women to volunteer to assist with telephone counseling line. All volunteers receive over 30 hours of training. Call the Volunteer Services Coordinator at 612/871-0118.

Encourage Children's Immunization Against Disease
Children should receive 80 percent of their vaccinations before age 2 so they will be protected against disease during the preschool years. In Minnesota, only 61.4 percent of 2 year olds are immunized. Rates vary widely by age, location, and population group—from as low as 14 percent in some communities to 78 percent in others.

Primary responsibility for immunizing children is fragmented. Providers often expect parents to own the responsibility; while parents believe if their children have seen a doctor, their shots are up-to-date. It is everyone's responsibility. For more information, contact your local community health agency, or: Children's Defense Fund—Minnesota, 550 Rice Street, Suite 104, St. Paul, MN 55103. 612/227-6121.

Getting a Life
(Part Two--Conclusion)
by Ann Turnbull

After a year in Washington, D.C., our family moved back to Lawrence, Kansas. Jay had graduated with his class, and had the support of his classmates. My worries about his possibly having a seizure or having a behavior problem did not materialize at the graduation ceremony. We realized the importance of relying on ordinary people, and that it doesn't take a specialist.

Getting Friends

Jay was 22 and he'd been kicked out of the only adult program in Lawrence, and they weren't going to let him back in; we wouldn't have it if they did. So, it was our job to figure out how to create a life in a very different way.

The first person we found when we moved back to Lawrence was Chuck. The best thing we could think of to start with was a paid friend. Chuck would take Jay to a fitness club and they would work out. I wouldn't have believed it before we started on this path, but we ran into the most wonderful surprises.

It happened that Chuck was an advisor at a fraternity on campus and so he knew 85 guys who were all Jay's age. Jay is really good in music—that's his best connector with other people. There was usually music at the fraternity house, and so Jay started meeting some of the guys. One of the guys he met was Pat. Pat was having some academic difficulty, and was looking for himself.

Pat needed Jay as much as Jay needed Pat.

- That's what we've got to remember. We're not asking for charity or for someone to volunteer with our sons and daughters. We're seeking relationships. If there is anything that we've learned, it's that people who have been in a relationship with Jay have benefited just as much as he has. Once we start thinking in a different way of not asking for a favor, but creating an opportunity for everyone to get their needs met, then we start going about things differently.

Pat called us one night and said he had met Jay at the fraternity house and he really enjoyed doing some singing with him. He said, "Would you mind if I came over to your house and Jay and I spend time together?" What a wonderful phone call to get for parents whose son had never had a friend! How wonderful for Jay to have someone who wanted to be with him!

You think, oh that's fine, but that was a fluke. Pat, who started this arrangement with Jay, has now started a national organization called Natural Ties. He works to get campus organizations to take in one or two people with disabilities, and is working with organizations across the country. Young people love it!

Getting a Job

Then we started looking for a job for Jay. Rud and I helped to form a new private non-profit corporation to do supported employment. But it was not that group that helped Jay get a job, it was a family friend who came to us and said, "I think we ought to start practicing what we preach. If we're training people to work with folks with disabilities I think we should have someone with a disability on the staff." So, Jay was hired as clerical aide 20 hours a week. He now works 30 hours a week, and has very supportive co-workers. He loves his job and is proud of what he does.

One of the compelling reasons to start inclusion in the very earliest years is the people you make contacts with are the employers of tomorrow—that's how they get their foot in the job market.

Pat came to us after Jay had been visiting the fraternity about a year and a half and said, "I think Jay should move out. I think he needs to live on his own." That was really frightening with the bad experience he had the first time he did that. We said "That's interesting, but where do you think he might live?" Pat said, "I've talked to one of the guys in the fraternity and Corey said I want to be his roommates." (Getting A Life continued on page three)
Getting A Life continued from page two

Never in a million years did we think somebody was going to come to us and initiate a roommate arrangement! But that's what happens when you have friends. We often put friendship on the back burner and we think, we'll do "friends" after we do all the developmental skills. But if we do friends first and most importantly, then a lot of other things fall into place.

Getting A Home

We ended up working with our family finances in order to pay the down payment on a house that Jay pays the mortgage on with the money that he earns. At Jay's home, his name is on the mail box. He has two university student roommates and in lieu of rent and utilities they each provide him with about 12-15 hours of personal assistance a week. If somebody had told us eight years ago we would be doing this we couldn't have believed it! But what we have learned is that vision grows in ever-increasing circles and as you accomplish some things, then you begin to think something else is possible.

The question to ask is, why is every state in this country paying $50,000-$60,000 per year to keep people in residential institutions, when those same residential funding streams could be used in a different way to help people have homes of their own?

Jay has now had about six different roommates, each staying for about two years. He has a waiting list for roommates!

We've had a lot of support from Jay's group action planning team. Group action planning is family, friends, community citizens, and professionals coming together to do two things: to create social connectedness with each other and to creatively problem-solve. It's not stiff and terse, there's laughter, warmth, sitting on the floor, and food. It's about vision, and it meets frequently, not every six to twelve months: I can't help but wonder what Jay's life would be like now if this kind of community building had started 27 years ago.

Getting Around

I want to close with a story of one of the more profound lessons that I've learned in our wonderful journey over the last eight years. This lesson came from Shirley, who is the owner of the local taxi company.

We had been transporting Jay and his roommates had been transporting him. We know he needed to learn to use public transportation, but we were really afraid of taking the risk. I started worrying, what if the taxi driver stole his money? What if they teased him? What if they let him out at his house and they saw nobody was at home and went in and stole something? What if they sexually molested him? So then you get immobilized and say we can't be part of the ordinary community because all these terrible, tragic things will happen.

One day I decided I had to overcome my fears. The best way to overcome fear is to invite support. I set out to find the office of the A-1 Taxi Company. I found it out on the highway, a rickety old-trailer, where Shirley was sitting at a dilapidated desk, dispatching the taxis. I sat down and introduced myself, feeling very uncomfortable, like I didn't really know how to invite Shirley's support. So I started telling Shirley a little bit about Jay and she started asking me questions. I told her my worries.

She was doing all this active listening and saying, "I understand, I'm a mother. I don't blame you, I feel the same way. Is there anything else you're worried about? Tell me more." So she did this 40 minute counseling session. She gets all my worries out and she's nodding and understanding and patting me and giving me Kleenex. She asked, "Is there anything else?" I said, "Shirley, I told you everything."

Then she pulled her drawer out and took out these little pieces of construction paper. They were green and wrinkled. She started giving me these pieces of construction paper.

I said, "Shirley, what is this?" She said, "Ann, you have given me your red cards. Your red card of worry, your red card of concern, your red card of not knowing what to do. This is my green card of friendship. This is my green card of understanding, this is my green card of support, and this is my green card of help."

The tears were just coming down my cheeks and I said, "What are you saying to me?" She said, "Every day when I get up, I ask the good Lord to let me give as many of my green cards as I can and to take as many red cards as I can. Thank you, Ann for bringing me your red cards and thank you for the chance to give you my green cards."

Boy, did I learn. I was sitting there, awed by this ordinary community citizen who has profound wisdom about what it means to support people with special needs. Then she started telling me how she was going to handle every one of my concerns. She wanted to match Jay with one driver and then two and three others. She said, "I can't tell you today who I'm going to match him with. I need to think about it, but I'll call you in 24 hours." She called the next day and told me she was going to match him with Jim. She said that Jim asked her why she chose him for this.

And she said, "I just looked straight at him and I said Jim, you need a friend as much as Jay Turnbull needs a friend."

Shirley understands what reciprocity is. Shirley understands what goes around comes around. Shirley understands this isn't volunteer charity. We're building relationships where everybody has something to gain.

[This article is from a presentation made by Ann Turnbull at West Virginia's Early Intervention Summer Conference (1994). Ann and her husband, Rud, direct the Beach Center on Families and Disability at the University of Kansas, and are the parents of Jay, a young man with developmental disabilities. Special thanks are extended to Ann Turnbull and The Arc of Harrison County, Clarksburg, West Virginia, for permission to reproduce their article from Fair Shake, Quaterly Magazine of West Virginia's Fair Shake Partnership (Fall 1994).]

Event


Editors note: Futurity is not published in January and July, so please have a safe and prosperous new year!
Lending Library

The following resources are available on loan; publications for three weeks; videotapes (VHS 1/2" cassette) for two weeks. The only cost to the borrower is the return postage.

Early Childhood: A Policy of Inclusion (videotape, 23 minutes), Minnesota Department of Education, 1992. Several schools in Minnesota illustrate the positive impacts made in the lives of children and their families through a policy of inclusiveness.

Families Facing Transition (videotape, 25 minutes), Beach Center on Families and Disability, University of Kansas. Powerful interviews with three families who confront change when youth with disabilities make the transition to adulthood.


Futurity Available on Audio Cassette

Please tell your friends and associates who do not read print that they can request this monthly newsletter on audio cassette. Call: 612/296-4018 (voice); 612/296-9962 (TDD).

Federal Grant to Provide Respite Care for Children with Complex Health Needs

The Department of Human Services recently received a federal grant of $200,000 to enhance existing respite child care services to serve children who are considered medically fragile. The funds are derived from the Temporary Child Care for Children with Disabilities and Crisis Nursery Act through the U.S. Department of Health and Human Services, Children's Bureau. Minnesota competed with other states for this grant.

Community programs will focus on expanding options through existing child care services (i.e., services to families and day centers) and will serve communities of color and families who have been unserved or underserved.

A request for proposals will be announced by the Department within the next month to solicit interest from providers and other interested parties. Projects are expected to influence system change as well as to design services that are more family-friendly. For more information, contact Suzanne Pollack, Minnesota Department of Human Services, 444 Lafayette Road, St. Paul, MN 55155. 612/297-3634.

Council Publications in Alternative Formats:
1) Friends: A Manual for Connecting Persons with Disabilities and Community Members, Human Services Research and Development Center, on audio cassette;
2) Futurity, on audio cassette and is available through DRAGnet and Children, Youth, and Family Consortium Clearinghouse (electronic bulletin boards);
3) It's Never Too Early, It's Never Too Late: videotape available with closed captions; and publication available on audio cassette;
4) Making Your Case, Braille, computer disk, and audiotape;
5) Shifting Patterns: publication in Braille and on audio cassette; and videotape with closed captions;
6) Minnesotans Speak Out, Summary of Town Meetings, audio cassette; and
7) Read My Lips: It's My Choice, on audiotape.