Personal Futures Planning

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Shifting





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Governor's Planning Council on Developmental Disabilities

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27–28 National Survey of Shifting Patterns

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Looking at New Patterns

In 1990, the Administration on Developmental Disabilities, U.S. Department of Health and Human Services, issued a request for proposals related to educating policymakers. The Minnesota Governor's Planning Council on Developmental Disabilities responded to the request, and successfully competed for the grant.

The goal of the Minnesota Council's proposal is to promote and strengthen advocacy and empowerment skills of individuals with developmental disabilities and their families, and thereby enable them to influence critical policy decisions.

The activities of the project have included the following: • A survey of "best practices" in empowerment and self advocacy. Contact was made in each state with the developmental disabilities council, the university affiliated programs,

and a major consumer / parent organization. • A National Panel of Experts was convened to review the results of the survey, and select appropriate models for publication. • The preparation of two videotapes and this publication to present and discuss approaches to empowerment and self-advocacy.

Patterns of Many Shapes and Colors

One way to recognize that there is something new in the air, a major shift in the works, is to see the emergence of a new crop of buzz words. The words "empowerment," "self-determination,""self-transformation," and "autonomy" are not new. What is new is the frequency with which they are used in today's discussions about people with developmental disabilities. What is really new is the shifting patterns that such concepts represent. Recent actions about empowerment, self-advocacy, and self-determination have helped to re-focus our vision of what is possible.

For the purpose of this study, empowerment is defined as processes whereby individuals achieve increasing control of various aspects of their lives and participate in the community with dignity.

Self-determination is "a ten dollar word for choice... it is another word for freedom... a life filled with rising expectations, dignity, responsibility, and opportunity... a chance to live the American dream." (*Williams, 1989*)



There are a number of key concepts which are central to all of these attempts at definition. Private competency without public opportunity will not yield self-determination. Selfdetermination also depends upon the capacity of the external environment — of society — to permit and foster a wide range of choices. *(YMCA, 1991)*

At the personal level, people can develop the capacities and competencies of empowerment and self-determination only in themselves. People empower themselves. Others can assist individuals to gain the skills, knowledge, capacities and allies they will need to take control of their lives, create and take advantage of opportunities, and overcome barriers.

Empowerment and self-determination have much to do with: • Vision — having and being able to dream about what we want our lives to be like; • Choice and the right to make decisions for ourselves; • Power — control over resources which are necessary to act on our choices and decisions; • Relationships — being our own person in relationship with others.

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The Shifting Pattern

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Beliefs and Attitudes: Individuals			
From		То	
Feeling hopeless		Feeling hopeful	
Self-doubt	00	Belief in self	
Self-blame		Promoting the possible	
They owe me"; blaming others		I am responsible for the future; take control of own life	
Seeing deficits		Seeing strengths	

Beliefs and Attitudes: Services and Professionals

То

From

Professionals know better than parents or other lay people () People have different kinds of knowledge Reliance on experts () Reliance on the "common-wealth" in communities "We" choose for "them" () Consumers choose for themselves Power over () Power with and among

Beliefs and Attitudes: Community

FromToExclusion ("we" - "they")Inclusion ("all of us")Differences as inadequacyDifferences as assetsOne cultural perspectiveMulticultural perspective

(Adapted from Cornell Empowerment Project)



"You go through Partners and you come out thinking you have to change the world."

What Is This All About?

Key Concept: Partners in Policymaking teaches individuals with disabilities and family members to be community leaders. The program is designed to provide information, training, resources and skill building in two areas: a) what is state-of-the-art, and b) how to influence public policy. Individuals then use these tools to obtain better services, political advocacy, policy development and change, and

community leadership.

Partners in Policymaking is dedicated to assisting individuals and families to change the system. The intensive course provides 128 hours of instruction over eight weekends.



Sue Swenson's activism after Partners has brought Charlie to an inclusive classroom in his neighborhood school.



"It restored a sense of independence to our family, through increasing options for Charlie" – Sue Swenson



"I'm not changing the world alone, but I'm doing my part. To me that really means something. I think to Charlie that really means something."

Each of the sessions is devoted to a specific topic or level of government. Participants are given and complete assignments, such as serving as an intern with a public official. The overall goal is to reach a productive partnership between people who need and use services for developmental disabilities, and the people who make public policy.

Partners in Policymaking is all about providing information and skills training so people with disabilities and their families can pursue their own agendas.

"I've been on national committees, state committees, county committees... I've now decided that I want to run for the state legislature" – Linda Rother

The Shifting Pattern

From The system sets the agenda for individuals and families		To Individuals and families setting and pursuing their own agendas
A focus on information to individuals and families so they will know what the experts think is best, and act appropriately A focus on changing individuals and families	*	A focus on skills, competencies and knowledge so that individuals and families can set and pursue what they think is best
A focus on individuals and families as informed followers A focus on self-improvement		A focus on individuals and families changing the system and public policy Individuals and families as leaders
		A focus on self-determination, self-creation, advocacy and system improvement

Does It Make A Difference?

Partners in Policymaking programs have been offered in several states, and another twenty-four states are joining the effort in 1992 and 1993. The feedback from the individuals and families who have participated now fills volumes.

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"I have spoken to other parents, professionals, organizations and public officials."

Rodney, Second Grade: Rodney was placed in a self-contained unit for children with severe mental retardation, non-verbal or behavior disorders. Educational activities were the typical nut and bolt screwing, lacing cardboard shapes and peg boards. His behaviors included screaming (his most effective and the one that brought him fame), biting, kicking, and hitting.

He endured being locked in a medieval contraption where he couldn't raise his arms or see out. He endured many a take-down procedure and adults screaming in his face. Along with aversives, psychotropic drugs were used to control Rodney.

Rodney, Third Grade: Rodney entered the double doors of his neighborhood school. Rodney was emancipated from the den of aversives, program plans, and meaningless tasks. He was introduced to the freedom and innocence of just being a child. He no longer was a diagnosis leading a programmable life.

Rodney participates in sports, has been in two class plays, has been invited to parties and over to friends' houses, has had to give a campaign speech with augmentative communication, has had peers support and encourage him, and has been introduced to the alphabet and numbers. Rodney talks in sentences now, and no longer takes Thorazine. He was given his life back thanks to Partners in Policymaking, wrote his mother, a Partners graduate fromTexas.

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From parents of children with disabilities:



"Partners is where I learned the things that I apply every day to my students and to the campus and community in general"– Roberta Juarez

"We often feared how our baby daughter would suffer from having a brother who, because of his disability, would restrict her life and embarrass her in front of her friends. Those are nightmares that will never come true.
"I have spoken to other parents, professionals, Chambers of Commerce, school boards, organizations and public officials. I plan to continue my work in advocating for my son and others with disabilities." "With Partners in

in advocating for my son and others with disabilities." "With Partners in Policymaking I have learned about true quality of life and that "just a mom" can do anything and get results. The experience I have gained has allowed me

to speak with confidence and knowledge."

From individuals with disabilities:

"It sounds simple but probably the most important thing one can do for oneself is to be able to say 'I want' or 'I need.' If you can relate that information in a convincing and assertive

manner, then you've pretty well got it made."

"I think that Partners is where I learned the things that I apply every day to my students and to the campus and community in general. Without it I



"It has opened a whole new world of networking with other people with disabilities" – Kurt Greniger, cable show co-producer

would definitely not be doing what I'm doing today and having so much fun doing it."



"We identify what services the person requires, and how we should work together to support the person."

What Is This All About?

Key Concept: Individuals and parents receive training information and supports to more fully participate in case management for themselves or their sons and daughters with developmental disabilities. Case



"Just to be able to spend some time together with my wife...because of Diane's being involved in Parents as Case Managers, we were able to get some of the services we needed" — Paul Roth

management is improved by informed decision making by the individual and family, thus enabling them to hold service providers accountable for the outcomes identified in the individual's plan.

In many states, case management is a service mandated by legislation. The key components

of case management are accountability, accessibility, and coordination. Individual plans are an integral feature of case management. They identify what services the person requires, and how they should work together to support the person.

The fundamental notion of Parents as Case Managers is that individuals and parents, in fact, can be the case manager. People with disabilities and families can handle the choices and decisions



Diane Roth (right) is working with colleagues to bring Parents as Case Managers training to her rural area.

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"It gave control back to our family" — Diane Roth

involved, as well as the responsibilities of professional case managers. Federal law describes the case management responsibility as a "continuing, perhaps lifelong, relationship." Clearly, the individual and family are in the best position to maintain that relationship.

Because case management is often a mandated service, if individuals and families are to be their own case managers, then their status must be recognized by the state, and agencies with whom they come into contact. Parents as Case Managers projects may involve the following features: • Officially recognizing individuals and families as case managers. • Providing training and information to develop the competencies of individuals and families in the following areas: case management; rights and responsibilities as they relate to persons with disabilities; data privacy; state-of-the-art service delivery and philosophy; quality indicators; transition; and inclusion. • Producing and distributing resource guides and information packets to keep individuals and families informed of new developments and ideas. • Providing ongoing advice and support to participants, including a stipend to support their participation as case managers.

The Shifting Pattern

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From		То
Professionals planning for people		Individuals and families planning for themselves.
Reliance on over-worked, under-trained staff with a high rate of turnover		Reliance on the lifelong commitment of individuals and families to their own lives
A view that only professionals can be responsible		Respect for the fact that individuals and families have a vested interest in acting responsibly on their own behalf
Case management as a means to let people into existing services	*	Case management as a means for individuals and families to organize services in response to their needs and dreams
	®	

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of parent power."

An evaluation of a Parents as Case Managers project indicates that the project's program made an impact on people in three different areas. The project provided available information for the participants and improved their roles and family interactions; it provided emotional and instrumental support to the participants; and it helped the participants be more knowledgeable, self-assured, and decisive. • It helped the participants link with social resources and build their social networks, informal (e.g., connecting with the other parents) and formal (e.g., connecting with the other professionals) networks. Parents as Case Managers were able to obtain additional services for the sons and daughters, were more satisfied with the services they received, and believe that they have improved accountability by improving the quality of their children's lives. Testimony of the participants involved indicates important consequences in a number of areas: •I needed to come to the training today, to get another jolt of parent power.

• In the past, I felt alone coming from a rural area; now I don't because of the group of parent case managers. • A year ago I needed to have a legal advocate sitting next to me at a conference to do all the talking. Now I can go to a conference alone, and I feel confident with my advocacy skills. • We have received more services, and the system seems to move faster now. I am an organized, informed team member at my child's team meetings, with a broad vision of the possibilities and how to accomplish them for my child.



"It's giving you the means and the power to do what's best for the individual" — Bill Meyer (with son Max)



The focus is on developing a network of friends and relationships.

What Is This All About?

Key Concept: Personal Futures Planning is a process to create a vision of a more desirable future for individuals with developmental disabilities. It focuses on the unique gifts and capacities of the individual instead of deficits. It is a map for the individual's journey toward a better personal future. A Personal Future Plan is developed by a group of people who care about the individual. Once the plan is developed, the group continues to meet for as long as is necessary to support the person in moving toward the better personal future.

Personal Futures Planning is: • A tool for fostering new ways of thinking about people with

developmental disabilities. • An opportunity for people with disabilities to develop personal relationships, have positive roles in community life, increase their control of their own lives, and develop the skills and abilities to achieve these goals. • An ongoing problem solving process. The plan changes as new opportunities and obstacles arise. • An ongoing commitment by a circle of friends or a personcentered team of people on the life and future of an individual.



"It's helped me get where I am today" – Dan Crannell



It creates visions and

captures dreams.

Personal Futures Planning, at its heart, is a way that individuals with disabilities, their friends and family, can take charge of defining what the future should be like for the individual. The focus is on what must happen so that the individual can fully participate in and be valued



A celebration of people

by the community. The process identifies and builds on the strengths of the person.

Personal Futures Planning looks for doors and opportunities. It creates visions and captures dreams. It continually strives to be both visionary and extremely practical. The planning process develops a true picture of the person, and describes the best possible future

of the person in community. It then identifies problems blocking that future, and opportunities for progress.

The Shifting Pattern

From A professional team, to which families and individuals may be invited		To A team of family and friends, to which staff who are close to the individual may be invited
A circle of professionals (who may see the individual at the center of the circle)	() ()	A circle of friends who join efforts with the individual
A focus on services into which the individual can fit		A focus on how the world needs to work so the individual is a member of and contributor to the community
A preoccupation with test scores, problems, weaknesses, and paper compliance		A preoccupation with strengths, gifts, capacities What the person has to offer and build on
A focus on what "is"	*	A focus on dreams, and a vision of what "must be"
A view of life as defined by services	÷	A view of life as defined by relationships, community, choice, competence, a home, a career, a future



Making A Difference



Dan Crannell met with family members at the home of his brother for a Personal Futures Planning review.

Personal Futures Planning can make a difference in three different ways: in the effect of being vision focused and person-centered; through the changes in the person's life which result from actions taken; and by changes in services and the system in response to the plan.

Personal Futures Planning brings people together. It calls on people to act as friends, rather than staff. It gets people organized for action.

• Bill's parents had been trying for years to get him out of the institution. He was very aggressive. He was straitjacketed and "treated" with electric shock. Their efforts to find an agency in the community that would help were always met with a "no"; Bill was too much of a challenge. A group of ten friends—family, neighbors, and some professionals who had known Bill at various times—got together to plan for Bill's future. For Bill and his parents, this was the first time people had gotten together to say "yes." They found new energy and new hope. After a year of planning and following up on the plans, Bill lives with another person in a townhouse in his community. He has been aggression-free for a year. He regularly volunteers at a local food bank. He often rides his bike several miles to visit with his parents.

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"It allows the parents to be more in

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control. It allows you to maintain

your self-respect."

The Voucher System



What Is This All About?

Key Concept: Families and individuals with disabilities are given the responsibility, authority, money, and ability to buy what they want, need and prefer.

The voucher system is a remarkably simple idea—families are given direct access to funds which had been controlled by government.



Thanks to Vouchers, Robbie Johnson has had the same respite care giver -Jack Thompson – for three years.

Families are offered the opportunity to participate in the voucher program. Each family is allotted a certain amount of money for the year. This might be based on previous amounts received, the family's estimate of what it will need for the year, or a combination of both. The family decides what is needed; orders what is needed; pays for it; and is reimbursed from its pool of funds.

There are four underlying principles to this approach: • It is important to have a child grow up as part of the family. • Families know better than anyone what they need to stay together. • Families can be trusted to make the right decisions. • Families will stretch their dollars.

"We get probably

three times more

respite care than we

got before vouchers."

The Shifting Pattern

From No choice	.	To Choice
Being forced to take what you can get, not what you want		Families and individuals defining what they want
Authority, money and decision in hands of government or providers		Families and individuals having the responsibility, authority, money to buy what they want, need and prefer
Priorities defined by government and agencies		Priorities defined by families and individuals
Services and supports provided by staff and professionals of agencies		Services and supports provided by formal and informal sources

Making A Difference



Vouchers enabled Wallya Flowers to supplement her daughter's diet and to purchase exercise equipment for therapy at home.

The voucher system has made a difference from three perspectives: It has increased use of informal and alternative sources of support; it has made positive changes in the lives of individuals with developmental disabilities and their families; and it

has begun to change the nature of the system.

The single biggest category of expenditures in voucher systems has been respite care. Time and again, the arrangements were with informal and alternative sources. One family with seven young children was able to hire a family friend to babysit for the entire group when the parents went out to dinner.



The parents of one young girl rarely went out together because of the difficulty at meal times. They were disappointed in county providers because of the turnover in personnel: they had to constantly train new staff to care for their child. With voucher funds, the couple hired a neighbor who has known the child for many years.



The participants in one county's voucher project reported success in changing their control over the rest of their lives. One mother said that

Rachel Esparza can play in her backyard now, thanks to a sidewalk paid for with Voucher funds.



Some parents use a portion of their children's Voucher allocation to let them participate in community activities.

respite for her adult daughter was the biggest need. "We've gotten much more respite than ever...it allows us to keep up with our daughter." She also said that the flexibility of the funds allowed her to find a provider who can come in the evenings and weekends. "It's kept our (marital)

relationship going."

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Ann Esparza purchased software for her daughter Rachel using Voucher funds, then shared the software with Rachel's school.

partnerships for life.

What Is This All About?

Key Concept: All youth, including youth with disabilities, have the capacity to be leaders. Youth with disabilities can play a vital role in changing systems and policy so as to promote the inclusion of youth with disabilities in the social, economic, political, and spiritual life of the community, and their contribution to those areas of life. The cooperative efforts of and friendships among youth with and without disabilities can change the nature of community life for generations to come.

The focus of youth leadership and self-determination is wide and varied: • To foster integrated and respectful friendships among individuals • To develop skills among

youth for leadership and self-determination • To promote access to and inclusion of youth with disabilities in existing youth programs and education • To develop the capacity of services to respond to youth with diverse needs • To provide an opportunity for youth to participate in policy issues.





". . . then taking that step, then another . . ."

"... Eric, taking the first step and saying he would not take another."

These elements involve three critical ingredients: the development of skills, competencies and knowledge among youth with disabilities —tools for self-determination, leadership and change; the development of friendships, relationships, and alliances between youth with and without

disabilities — partnerships for life and change in the lives of youth with disabilities; and creating opportunities to act on decisions and choices.

There are a wide range of activities and approaches that can make up youth leadership and self-determination programs: • School partnerships: Work with youth, teacher, parents and school staff to: • Identify issues and opportunities at the school in terms of integration and

youth leadership. • Use a variety of contexts (the classroom, extra-curricular activities and clubs, or existing friendship networks among young people) and methods (peer friendship, circle of friends, youth service clubs) to develop integrated youth groups, and



"Those are the success stories" – YMCA program director.

friendships among youth. • Train staff in both schools and community organizations in a variety of skill areas such as self-advocacy, personal futures planning, facilitating relationship building, and developing career vision. • Outdoor leadership programs: Involve youth with and without disabilities in activities that build self-determination skills, and foster appreciation for the diversity of individual talents. Such programs combine adventure-based experiences, team building, and workshops on assertiveness skills, cultural awareness and leadership. There are many occasions and places through which young people can enter into relationship with a youth with disabilities, such as the neighborhood, youth clubs, part-time jobs, church and church youth groups, community sports teams and recreation events.

The Shifting Pattern

From	То
Peers as helpers and mentors	Peers as friends
Youth as irresponsible	Youth as responsible
Youth with disabilities as dependent	Youth with disabilities as leaders
Youth with disabilities as "other" to be seen as separate	Youth with disabilities as "one of the group"
Skills for daily living	Skills for leadership and self-determination.
Youth as today's problems to be solved	Youth as problem solvers, and the leaders of the future

Making A Difference

In one program, a summer youth leadership camp included youth with disabilities for the first time:



....You have to believe in your friends - and in yourself.

"The young people came away realizing that a young person



Traversing the bog means more than an exhilirating ride...

with a disability should be treated the same way that they want to be treated. The young people with disabilities did

some things they probably thought they would never, ever

do. Like Eric, climbing the tower—taking the first step and saying he would not take another step. Then taking that step, and taking a third step..."

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"People with disabilities are in the best position to make choices for themselves."

What Is This All About?

Key Concept: People First is an international movement of people with developmental disabilities advocating on their own behalf. People with disabilities are seen as capable of representing their own best interests and exercising their own choices.

Self-advocacy training assists people with developmental disabilities to make and express choices for themselves, to know and assert their rights, to organize and form alliances, and to have an impact on public policy.

People First takes a few very basic principles quite seriously: People with disabilities are people first. They should be seen for their abilities. They have the same needs as everyone else — a home, a job, an education, love and friendship, dignity, a good time, a decent standard of living. People with disabilities are in the best position to make choices for themselves, to speak on their own behalf, and represent their interests.

As with other people, people with disabilities often require the help of friends and allies in acting on their choices and defending their rights. People First groups often have advisors to help them get organized, to interpret information that is complicated, and to follow up on issues. Advisors participate to provide advice, not direction.

Self-advocacy training is often a common feature of People First groups. People First members and invited trainers give workshops, assist people to learn while they are engaged in advocacy activities, review what is happening so lessons can be learned, and so forth. In some cases, People First members travel across the country, or closer to home, to provide training and consultation to local groups.

The Shifting Pattern

From Having one's best interests represented by others, usually families		To Making choices and representing one's own interests
Being seen and treated as a client	(and the second	Representing oneself as a citizen and person with rights
Life skills training	*	Assertiveness and advocacy training
Being dependent and afraid		Being courageous and defending one another
Not being seen or heard		Having a seat at the Board table, being granted standing in the court, testifying before a legislative hearing

Making A Difference

People First groups engage in a variety of activities. For many members, a first act of courage is accepting the invitation to attend a People First meeting. Speaking up for the first time is another act of courage for many People First members. For many, it is a quick jump from speaking up with friends to joining a delegation to demand changes in services. The road is long; fear and intimidation abound.



"People First helps us to be good selfadvocates for ourselves, and to know what this community is all about" – Irving Martin



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People First members and groups have accomplished much at the service and system level. In various communities, they have demanded and won the right and support to work in the community; better working and living conditions; changes in government policy; and the right to be heard in court.

People First members have fought long and hard to escape the indignity of disability labels. Their declarations of dignity have meant that far fewer people use the derogatory terms — "the retarded," "the disabled," "the trainable." Instead, the minimum standard is now phrases beginning with "people with..." What is this all about?

A focus on the job as a means to produce a certain quality of life for the individual.

Key Concept: Individuals with disabilities have dreams and desires about employment. While supported employment has opened new opportunities for jobs, it has not always resulted in careers that are consistent with the objectives of the individual. Career Vision is intended to identify the career skills and goals of the individual and use those skills and goals to find employment. This results in greater job satisfaction for the employee, less likelihood of turnover, and a happier employee.

Career Vision is a tool that identifies career goals; determines job-related skills; brings together the various bureaucrats to cooperate on locating appropriate employment; and results in more job satisfaction for the individual.



Steven Hinderman is increasing his hours at Eastern Heights Bank to qualify for benefits.

Career Vision provides the information that enables employment, training and support resources to be more effectively tailored to the individual. It identifies ways that employment will improve the quality of life of the individual; and it ensures that the focus of the planning team will be on the unique interests, strengths, and wishes of the individual.

It begins with the creation of a dedicated support team whose members share a common purpose and goal. The team must include persons who know the individual best,



persons from his or her circle of support, and the individual. The team must agree that "It can be done," and be committed to pursuing and identifying the "how." Team members must be flexible and creative in their thinking, willing to brainstorm and to consider any alternative, no matter how unlikely it might first appear.

The individual and the team create a personal survey, gathering

Drad Duncan enjoys the office environment and the company of co-workers in his job handling recycling for an insurance company.

information about the individual's abilities, likes, and preferences. Also included is the person's job history, with attitudes toward different job tasks and environments.

Finally, the team identifies potential solutions that satisfy the criteria in the personal survey. For each of the solutions, the team creates an action plan that bridges the gap between the present and the future. Team members hold themselves accountable for implementing the action plans.

The Shifting Pattern

From A focus on the job as the end product	.	To A focus on the job as a rung in a career ladder
Viewing the person as a commodity that will produce a product or service for the employer	*	Viewing the job as a means to produce a quality of life for the person
A focus on molding the individual to the job	*	A focus on finding the job that will match the skills and goals of the individual
A team concerned with placing people in jobs		A team concerned with satisfying the needs of the individual



Making A Difference

Career Vision can make a difference because it identifies the quality of life outcomes sought through employment by bringing out the individual's unique interests,

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"This job has been a good match for Steven, and he's made an excellent contribution to the bank!" – Jenine Nordquist, bank official.

strengths, and career goals.

"Steven loves his work so much now that sometimes he has to be reminded that it's lunchtime. He has decided to increase the number of hours he's working each week, so that he becomes eligible for vacation time and a pension, and all the other benefits that the rest of the bank employees receive. He works hard and he deserves it!"



Each week, Rochel Turan, of Kaposia, inc., reviews Steven's progress with him in a brief meeting at the bank.

National Survey

The staff of the Minnesota Governor's Planning Council on Developmental Disabilities conducted a national survey of other councils, university affiliated programs, and consumer / parent organizations during 1991.

The purpose of the survey was to seek information about projects or activities that promote self-determination and empowerment. We urge you to contact your state council, university affiliated program, or protection and advocacy agency for further information. A list of projects identified by state respondents appears below:

Alaska	People First and Community Support Network
Arizona	Self-advocacy called OASIS (Organized Adults for Special Individuals in Society)
Arkansas	Family Leadership
California	Partners in Policymaking
Colorado	Partners in Leadership and People First
Commonwealth of Northern Marinana Islands	Special Education Conference
Connecticut	Partners in Policymaking, Coalition for Inclusive Education for Students with Disabilities, Circles of Support, Connecticut Union of Disability Action Group, People First, Personal Futures Planning, and Self-Advocacy
Delaware	Partners in Policymaking
District of Columbia	Parent Advocacy Project and Citizen Advocacy
Florida	Independent Employment
Georgia	Parents Educating Parents, Quality of Life Project, and Partners in Policymaking
Hawaii	Project Po'ohala (family support) and Partners in Policymaking
Idaho	Kid Power, Circle of Friends, People First, and Family Support
Illinois	People First, Parents for Inclusive Communities, Partners in Policymaking, Leadership Coordinating Group, Choice and Integration Project, Family Support Network, and Self-Advocacy Support
Indiana	People First, Partners in Policymaking
Iowa	Partners in Policymaking, Family Support Initiative and Empowerment Project
Kansas	Advocacy Training and Early Childhood Institute
Kentucky	Statewide Parent Network, Self-Advocacy Project, and Life Planning (Personal Futures Planning Adaptation)
Louisiana	Partners in Policymaking, Community and Family Support System Plan, and Family Resource Centers

National Survey

Maine	Advocacy for Change (family leadership)
Maryland	People on the Go (self-advocacy), Coalition for Integrated Educational Opportunities, and the Parent's Place
Massachusetts	HIV /AIDS and Disability Network, Family Support, and Leadership
Michigan	Parent Support and Advocacy, and Self-Determination Training
Minnesota	People First, Partners in Policymaking, Advocating Change Together, Youth Leadership, Voucher Project, Parents As Case Managers, and Personal Futures Planning
Mississippi	Family Support Program and Coalition for Citizens with Disabilities
Missouri	Show Me Choices, How to Be an Effective Board Member Training (self-advocacy), and Legal Empowerment for Disabilities
Nebraska	Project Parent, Family Training Workshop Series, and Assistance Network
New Hampshire	Family Leadership, Statewide Linking Network, Citizen Advocacy, and Self-Advocacy Training
New Jersey	Person Centered Planning and Project Take Charge
New Mexico	Partners in Policymaking
New York	Partners in Policymaking, Family Support Project, Minority Partners Regional Initiatives, Choice Project, and Self-Advocacy Association
North Carolina	Parent Training and Self-Advocacy
Ohio	Family Leadership, Focus, Inc. (self-advocacy), and Leadership Advocacy
Oklahoma	CARE Councils (Community Awareness Resources Education Councils), Parent Training Project, Chickasa Project (parent training for children with severe physical disabilities), and Partners in Policymaking
Oregon	Family TIPS (Transition Planning and Support System), Consumer Involvement Fund, and Community Partnership Project
Pennsylvania	Parent Network in the Community, Permanency Planning, Education and Leadership Project, Empowerment Curriculum, and Partners in Policymaking
Rhode Island	Community Organizing for People with Disabilities
South Carolina	Our Voices County, Parents Reaching Out to Parents, and National Clearinghouse of Information and Resources
South Dakota	Independent Living Skills Training, Family Advisory Boards, and Partners in Policymaking
Tennessee	People First, Coalition for Tennesseans with Disabilities, Family Project, Tennessee Initiative on Employment, and Partners in Policymaking
Texas	Partners in Policymaking, Community Connections, and Coalition of Texans with Disabilities
Utah	Utah Legislative Coalition and Family Support
Vermont	Vermont Coalition for Disability Rights
Virginia	Leadership Workshops and Consumer Empowerment Project
Washington	Leadership Institute, People First, and Consumer Empowerment Projects
Wisconsin	Supportive Parenting Project, STARS (Sexuality Training for Adolescents), Personal Development Project, Full Citizenship Initiative, and Mini-grants to Visionaries
Wyoming	Parent Support and Annual Family Conference

The U.S. Department of Education Office of Special Education Programs funds projects in the area of self-determination



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A list of references cited in Shifting Patterns is available from the Council office.

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