

# *COMMUNITY RESOURCES*

## FOR PEOPLE WITH AUTISM

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### *Transition ~ Person Centered Planning*

- Person-Centered Planning: A Tool for Transition (source: National Center on Secondary Education and Transition)
- Building a Future Requires Vision, Planning (source: Newsline)
- Here's What I Dream~A Look at Person Centered Approaches (source: Irwin Siegel Agency)

*Community Resources for People with Autism  
116 Pleasant St.; Ste. 366  
Easthampton, MA 01027  
(413) 529-2428*

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## National Center on Secondary Education and Transition

### Parent Brief

#### *Promoting Effective Parent Involvement in Secondary Education and Transition*

February 2004



## Person-Centered Planning: A Tool for Transition

The expression, “It takes a village to raise a child,” is never more true than when talking about a child with a disability. Young people with disabilities need a support system that recognizes their individual strengths, interests, fears, and dreams and allows them to take charge of their future. Parents, teachers, family members, and friends in the community who offer informal guidance, support, and love can create the “village” for every child.

Yet when young adults with disabilities are preparing to make the transition from high school to work or postsecondary school, their “village” may be forgotten in the rush to secure new services from programs and systems that provide support for adults with disabilities. These crucial supports may include vocational rehabilitation, day training programs, Social Security, Medicaid waivers, housing, and transportation support. In contrast to a young person’s informal support network, systems tend to use relatively impersonal and formal methods of assessment. Case managers, vocational rehabilitation counselors, and county social workers often have large caseloads as well as a limited amount of time to know the individual needs and abilities of each student on their caseload.

Responsibility for maintaining the “village” is usually left to the family or parents of the student who is graduating. However, parents have little time to become experts on the range of supports available to their child after high school. It is not surprising that the invaluable, informal supports available from a young person’s “village” often remain untapped or underdeveloped while families focus on accessing adult services.

This does not need to be the case. Use of a person-centered planning process with young adults with disabilities as they go through transition can unite formal and informal systems of support. By combining resources and working intentionally toward a common goal, families and professionals can achieve more positive outcomes for youth with disabilities, while at the same time putting long-term community supports in place.

### Person-Centered Planning

The Individuals with Disabilities Education Act (IDEA '97) requires that a student’s Individualized Education Program include transition planning by age 14 or earlier, if appropriate. This plan should reflect a student’s interests and preferences, current accomplishments and skills, what they still need to learn, as well as what they want to do in life. This can include a range of goals—everything from the type of career the student would like to pursue to the kind of living situation he or she hopes to have. Person-centered planning is a way to identify a student’s individual goals and to help students, families, and professionals craft plans that will support students as they strive to achieve their dreams.

At its best, the person-centered planning process can strengthen the transition to post-school activities by:

- Enhancing the quality of assessment and planning activities for both high school transition services and adult service agencies serving youth with disabilities;
- Fostering positive working relationships between families and professionals;
- Providing a way for educators and case managers from other agencies to better coordinate their services;
- Connecting families to adult service agencies before a student leaves high school;
- Helping ensure that services support the youth’s goals and lead to successful outcomes; and
- Helping identify and cultivate natural supports in the community.

### Idea '97

## §300.29 Transition services.

(a) As used in this part, **transition services** means a coordinated set of activities for a student with a disability that-

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

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

(Authority: 20 U.S.C. 1401(30))

## §300.29 Transition services.

The IEP must include-

1. For each student with a disability beginning at age 14 (or younger, if determined appropriate by the IEP team), and updated annually, a statement of the transition service needs of the student under the applicable components of the student's IEP that focuses on the student's courses of study (such as participation in advanced-placement courses or a vocational education program); and
2. For each student beginning at age 16 (or younger, if determined by the IEP team), a statement of needed transition services for the student, including, if appropriate, a statement of the interagency responsibilities or any needed linkages.

(Authority: 20 U.S.C. 1414(d)(1)(A))

## Person-Centered Planning Action Steps

### Step 1: Choosing a facilitator

Parents and families can begin the process of person-centered planning for their son or daughter with a disability by choosing a facilitator. A facilitator needs to be a good listener, work creatively to shape the dreams of the individual, discover the capacities within the individual and within the community, and be a community builder.

**A facilitator can be a family member, school staff member, a service provider, or a consultant. It is helpful if facilitators have previous experience or training on conducting person-centered planning. Facilitator training is offered in many states through school districts or other publicly funded programs.**

### Step 2: Designing the planning process

An initial meeting to develop the personal profile usually occurs several days before the planning meeting so the participants have time to reflect on what is shared. The meeting takes about two hours.

Parents/families and the person with a disability will:

- Develop a list of people they want to invite based on their:
  - Knowledge of the person and family;

- Ability to make this process happen;
- Connections with the community; and
- Connections with adult service providers (if they will be involved in the future).
- Identify a date and time for the initial meeting and other follow-up meetings.
- Determine the place that will be the most convenient for everyone, especially the person with a disability.
- Discuss strategies that increase the participation of the focus person, the person with a disability.
- Decide who will take a lead in gathering information during the meeting and what person-centered process will be used (PATH, Essential Life Planning, It's My Life, or another).
- Develop a history or personal life story or profile of the focus person by everyone sharing past events in the person's life. The focus person's parents and family may share the largest amount of this information. Critical events, medical issues, major developments, important relationships, and more may be shared.
- Describe the quality of the focus person's life by exploring the following: community participation, community presence, choices/rights, respect, and competence.
- Describe the personal preferences of the focus person. Include both likes and dislikes to get a complete picture.
- Send invitees the personal profile.

### Step 3: Holding the meeting: Implementing the person-centered planning process

- Review the personal profile and make additional comments and observations.
- Identify ongoing events that are likely to affect the focus person's life such as conditions that promote or threaten health.
- Share visions for the future. Through brainstorming, imagine ways to increase opportunities.
- Identify obstacles and opportunities that give the vision a real-life context.
- Identify strategies and action steps for implementing the vision.
- Create an action plan. Action plans identify what is to be done, who will do it, when the action will happen, and when you will meet again. Identify action steps that can be completed within a short time.

### Step 4: Planning and strategizing at the follow-up meetings

Work the action plan. Implementing the plan can require persistence, problem solving, and creativity. Periodically bring the team together again to discuss what parts of the plan are working and what parts are not. Once more, identify what is to be done, who will do it, when the action will happen, and when you will meet again.

Make sure that at each follow-up meeting the team:

- Establishes the time and place of the follow-up meeting;
- Establishes the list of participants;
- Lists all activities that occurred in the past;
- Lists all of the barriers/challenges that occurred;
- Brainstorms new ideas and strategies for the future;
- Sets priorities for the next agreed upon time period (6 months/12 months);
- Establishes renewed commitment by those participating;
- Lists five to ten concrete steps for each person to follow;
- Establishes the next meeting time; and
- **Always celebrates the successes!**

Note: Adapted from Mount, B. & Zwernik, K. (1994). *Making futures happen: A manual for facilitators of personal futures planning*. Minnesota Governor's Council on Developmental Disabilities.

## Young Adult Participation in the Planning Process

It is critical for the young adult with a disability to actively participate in the transition planning meetings. This might involve advance preparation, such as asking the student to talk individually with each team member before the meeting or helping the student craft a written invitation for each team member. It is very easy for adults to take over, making the young person a passive observer instead of a leader in the process. The team must make conscious efforts to provide the young person with ways to express his or her own dreams for the future, agree or disagree with other members of the team, and be actively involved in the team's ongoing efforts. Students with all types of disabilities—regardless of the severity of the disabilities—should be included in the transition planning process.

Young adults also have a number of responsibilities when it comes to participating in and leading their transition planning meetings. They need to think about what they really want for the future, identify what kind of help and support they might need to achieve their goals, and come prepared to share this information with their team.

Despite growing interest in using person-centered planning to drive the transition process, it is not yet common practice. One reason for this may be that many people believe this process is too time consuming. What they may not realize is that person-centered planning may be more efficient in the long run. The best transition plans truly reflect student-family goals for the future, which helps the team avoid time-consuming guesswork. People certainly learn from their mistakes, but a person-centered planning process can help teams to produce a much more accurate reflection of the young adult's goals and at the same time, go to the heart of what is needed by the young adult and family much earlier.

## Adult Services Planning

In addition to the family, the young adult, and special educators, the person-centered planning process can also involve county case managers, social workers, vocational rehabilitation counselors, and health care professionals. Including adult service providers in person-centered planning can help ensure a seamless transition from special education to adult services. Just as person-centered planning can enhance the transition planning process for a student with disabilities, it can be a tool to improve individualized plans for employment (IPEs) as well as other adult service plans for young adults with disabilities who are eligible to receive those services.

## Developing Natural Supports with Person-Centered Planning

In addition to including professionals and service providers, it is essential that person-centered planning teams include individuals who are familiar with the abilities, interests, and needs of the young adult in work, school, or social settings, and who are willing to help. These supportive individuals or "natural supports" can be family members, friends, neighbors, former teachers, or other caring and knowledgeable individuals who know the young adult.

Forming the person-centered planning team provides families with an opportunity to involve individuals who want to help in ways that make a difference. These individuals, in turn, can often provide access to broader and more integrated opportunities in community settings than a professional can. Some examples of how an informal support person can help young adults pursue and achieve their goals include:

- A neighbor who helps a young person find movie theaters on nearby bus routes;
- A relative who talks with colleagues about job opportunities for a young adult who wants to work with computers; and
- Friends or family members who help find clubs—such as camera, book, hunting, or fishing—related to a young person's interests.

The insight of family and friends can complement and enhance the expertise of the professionals on the team. For example, the team might discuss how a person's strengths equate to job skills and how the person's interests and abilities match specific career areas, jobs, and employers. The team might also discuss other employment-related needs, such as transportation or assistive technology.

Involving friends and neighbors who are unfamiliar with traditional forms of service delivery can actually be an asset, because it can foster more creative problem solving. Relatives and friends can also help families develop a "safety net" of informal community supports to assist a young person when parents are not available or if formal supports break down.

## More Than a Series of Meetings

The team should meet as often as members and the young person want in order to discuss their goals and support needs. Follow-up meetings should be scheduled as needed to find out how the young adult is achieving those goals or if their goals have changed. However, no matter how often a team meets, a plan is just a piece of paper if it is not put into action. One way to make sure the plan leads to action is to have the young adult, family, or team choose a facilitator. The facilitator can lead the meetings by identifying and formulating questions during the meeting and organizing important points from general statements. The facilitator can also delegate responsibilities to other team members.

For example, if the team is focusing on employment after high school, the facilitator could have one person take responsibility for helping the young adult find an internship or job-shadowing opportunity. Someone else could help the young adult find appropriate transportation. Each team member assumes responsibility for a specific task that is outlined in the plan. At the next meeting, the team members discuss their progress and modify the plan as necessary.

It is a good idea for the team to have someone responsible (parent, facilitator, or a designated case manager) for follow-up—someone who can check with other members to see how they are progressing.

## What Happens if the Young Adult Has an Unrealistic Goal?

The team must determine its own comfort level with the goals of the individual. However, how the team feels about the goals and how the young adult feels may be two very different things. Supporting young adults to learn about and further explore their dreams for the future is the proactive solution to this situation. As a result of this exploration, a young adult may decide that his or her goal is not necessarily a good match. However, the exploration process can be a memorable learning experience, a valuable way of learning about one's self, and ultimately an important way of discovering other pathways to success. It is important to realize that failure is not necessarily something to be avoided; it is a natural part of life. More importantly, a person with a disability who is protected from failure is also protected from potential success. Helping young people with disabilities pursue challenging goals provides them with invaluable opportunities for self-discovery, as well as the opportunity to surpass expectations and to actually succeed in achieving their goals.

## Selected Resources on Person-Centered Planning

Many different person-centered planning tools have been developed that could be used in the transition process--

- MAPs,
- Personal Futures Planning,
- PATH planning,
- Essential Lifestyle Planning, and
- Dream Cards are a few examples.

The following are some online resources with more information on person-centered planning tools.

### Parent Center Resources on Person-Centered Planning

- [PACER Center](http://www.pacer.org/tatra/resources/personal.asp): <http://www.pacer.org/tatra/resources/personal.asp>
- [PEATC](http://www.peatc.org/NEXT_STEPS/Intro/brief.htm): [http://www.peatc.org/NEXT\\_STEPS/Intro/brief.htm](http://www.peatc.org/NEXT_STEPS/Intro/brief.htm)
- [IMPACT: Transition to Empowered Lifestyles Project Person-Centered Planning](http://www.ptimpact.com): <http://www.ptimpact.com>

### University and Government Resources on Person-Centered Planning

- [Beach Center on Families and Disability articles on Person-Centered Planning](http://www.beachcenter.org): <http://www.beachcenter.org>
- [Oregon Department of Education Transition Web Resources](http://www.ode.state.or.us/gradelevel/hs/transition/resources.aspx): <http://www.ode.state.or.us/gradelevel/hs/transition/resources.aspx>
- [Person-Centered Planning Education Site](http://www.ilr.cornell.edu/edi/pcp/): <http://www.ilr.cornell.edu/edi/pcp/>
- [State of Indiana Person-Centered Planning Guidelines](http://www.in.gov/fssa/disability/bqis/pcpguidelines.html): <http://www.in.gov/fssa/disability/bqis/pcpguidelines.html>

Mount, B. & Zwernik, K. (1994). *Making futures happen: A manual for facilitators of personal futures planning*. Minnesota Governor's Council on Developmental Disabilities.

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# Building a Future Requires Vision, Planning



*What are my dreams and visions for the future? What about middle and high school? What will I be doing after high school? What do I want to be doing and where will I live as an adult?*

Finding possible answers to these questions and choosing among them are important endeavors for all students. For students with disabilities, envisioning possible futures and choosing among them require complex considerations and careful planning. Plans and choices made during the school years are critical to a student's later success in life. Yet, all too often, what is learned in high school does not support students' visions for their future.

Terri McLaughlin, Federation Transition Specialist, encourages parents to work with schools to develop meaningful transition plans for their youth with disabilities. She compares developing a good transition plan to creating a structure or building a home: "You begin each process by dreaming. With the help of a good architect, a blueprint is developed, showing how the structure will reflect the lifestyle of the inhabitants. Next, you need a builder to ensure that each piece of the building process happens in the right order and on schedule. Individual effort and expertise and the careful collaboration of many committed people result in a structure that truly reflects the owner's vision."

McLaughlin concludes, "Transition planning is a collaborative process that is ongoing, student-driven, and outcome-based. Like a home, the outcome of a good transition plan is also a dwelling place, one made up of a collection of life experiences that reflect a person's hopes and dreams and that empowers the person to live them."

## Legal Requirements for Transition

As long as a student is eligible for special education services, federal and state laws require that transition needs and services be addressed in the student's IEP. *At age 14 years* or younger, IEPs must contain a "statement of the transition service needs of the student." Parents and students can use this requirement as an opportunity to begin developing a transition plan with school personnel. In fact, from age 14 on, the IEP meeting is often referred to as an IEP/ITP (for Individual Transition Plan) meeting. This IEP statement should begin with a vision of the future the student desires. The service needs identified should focus on the student's

course(s) of study and be integrated into the IEP.

*At age 16*, or younger if appropriate, the school should begin to include transition services in a wide range of areas. "Transition services" means a coordinated set of activities designed to promote movement from school to

such post-school activities as, for example, college, employment, vocational training, and independent living. Transition services the school should provide may include, but are not limited to: instruction, community experiences, the development of employment and other post-school living objectives, and when appropriate, the acquisition of daily-living skills and vocational assessment.

The statements of transition needs and services, which are the basis of a transition plan, identify what students need to experience, learn, and know to be prepared for a meaningful and rewarding adult life. For the eight years from ages 14 to 22, the *statements of transition needs and services are a formal, required part of the IEP*. As one grows and develops, so does one's vision for the future. As priorities, preferences, and dreams emerge and evolve, IEP/ITPs should be updated annually to reflect new priorities among the many components of an effective transition plan.

The Federation for Children with Special Needs, in collaboration with the Massachusetts Department of Education, is presenting transition workshops during the 1999-2000 school year in a community near you. These comprehensive workshops will guide parents and professionals as they develop IEPs with transition services for students with disabilities.

See page 13 or check out our website at [www.fcsn.org](http://www.fcsn.org) to see an updated list of training workshops, and mark your calendar now! For more information, contact Terri McLaughlin at the Federation's Boston office; 617-236-7210 or 800-331-0688, ext.185.

## SSI Rule Changes at 18

Another important consideration in transition is the student's status concerning Supplemental Security Income (SSI). When a student turns 18, the following changes to eligibility rules apply:

### For new applicants:

- Once students turn 18, their financial eligibility is no longer based on family resources, but is based solely on the student's income, resources, and living situation (even if the student continues to live at home).

### For students who have been eligible for SSI and must go through redetermination:

- There must be a severe impairment that limits the ability to do basic work activity.
- The individual must be currently disabled (determined by whether they are working and earning over \$700 a month).

For more information, check out [ruralinstitute.umt.edu/rises](http://ruralinstitute.umt.edu/rises) or call Maria Christina Vlassidis, Institute for Community Inclusion, at 617-355-4673.

## The Impact of Personal Futures Planning on Families

by Angela Novak Amado

Personal Futures Planning is an individualized, structured, possibility-based approach to life planning. The individual plan represents a vision for a more desirable future, developed by a group of people who care about the individual and are willing to assist in making the plan become a reality.

The process starts with a focus person, a group of people who care about the focus person, and a group facilitator. Large sheets of paper on the wall are covered with colorful pictures and statements. The first meeting, a Personal Profile, looks at a person's history, relationships, strengths, and gifts. In the second meeting, the group develops a dream or vision for a desirable future. People make commitments to certain actions to help bring the dream into reality. Then, the group continues to come together to share successes and failures and to continue to move forward.

Personal Futures Planning was developed by Beth Mount and John O'Brien, and has been used for more than 10 years in many different states. It can be used with any person of any age. It is often used to discover what's possible for people when looking from the perspective of the person's capacities rather than the traditional deficit-based planning approach, and to empower people who care. Persons with disabilities, service providers, case managers, and families, have all reported being profoundly impacted by the process. They can see people in new ways, understand people much differently, and be more inspired to realize much different dreams and visions for the person than what occurs in traditional planning processes.

The Minnesota Governor's Planning Council on Developmental Disabilities has sponsored three years of training in Minnesota on Personal Futures Planning. More than 200 people have received plans in those years, and many families have also been impacted. Some examples of the kind of differences the process makes for families and for individuals with disabilities are the following:

- **Transitions.** Personal Futures Planning is often used at different transition points, such as from early childhood to regular school programs and from school to adult services. It is also used for transition to new services, such as group home to apartment living and sheltered to supported employment. One example of using Futures Planning for transitions is Emily's parents and early childhood staff, who used the process to discover that it was possible for her to go to regular kindergarten. At the planning meeting, Emily's mother said: "We had hopes for her. But we never told people those hopes because we didn't think they could happen." Emily now attends kindergarten in a district that has never before served children with her severity of disability in regular kindergarten.
- **Services.** The Futures Planning process can often help clarify what the best situations for people could be. For example, Gary's family could not care for both Gary and his sister at home, and his mother would not hear of him moving to a group home. The planning group helped find a foster couple who lived near Gary's family and went to the same church. Gary's mother is now able to feel good about him living away from home.
- **How the Person is Seen.** In the Futures Planning groups, families and other group members often come to see the person in new ways, such as viewing them as more like other people and more capable. For example, a woman who had been living in a locked unit at a regional treatment center was thought to be helpless or dangerous; however, when she was pouring coffee and socializing at her planning meeting, family and other group members had their anxieties eased. They helped her move out of the center and back to her hometown.
- **Empowerment.** Through Personal Futures Planning, families can be empowered in obtaining support and in facing sometimes scary decisions and futures. For instance, Gordon's mother was empowered to move from just complaining to writing and getting others to write letters requesting more respite care.
- **Being Involved.** Often, the Futures Planning process has enabled family members to become involved again. The focus is on capacity and gifts, and the real interest is in a person as a human being, not just a "client" or "special education student". Through the process, group members often get excited about inviting family back into people's lives. For example, Pat's family members have been amazed to discover that the person they thought was "a vegetable" is very capable, and have been thrilled to reconnect with him as part of their family.

Personal Futures Planning as a process has brought people together who have traditionally been adversarial or focused on the service system. It has allowed them to see and care about others as real human beings. Through the process many individuals with disabilities and their families have been able to express wishes and dreams, and to have those dreams come true.

Angela Novak Amado is the Executive Director of the Human Services Research and Development Center, 357 Oneida Street, St. Paul, MN 55102. For further information on Personal Futures Planning contact the center, or see the Resource list on page 19 of IMPACT.

# “Here’s What I Dream”

*A Look at*

## Person Centered Approaches

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# **"Here's What I Dream"**

*A Look at*

## **Person Centered Approaches**

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"Balancing Consumer Choice and Provider Liability," John Rose, Irwin Siegel Agency, 25 Lake Louise Marie Rd., Rock Hill, NY 12775.

"Article 63 - Developmental Disabilities--Licensing Providers of Community Services," K.S.A. 30-63-21, Kansas Department of Social and Rehabilitation Services, Docking State Office Building, 915 SW Harrison, Topeka, KS 62974.

- Safety Matters Video
- Lifting and Back Safety
- Promoting A Positive Approach to Behavior Management
- OSHA Guidelines
- Staff Recruitment and Retention
- Other materials and videos are also available.

Please feel free to call 800-622-8272 to request further information on the above resources and other available services and materials.

## About the Authors

### LYNN RENO

*Human Service Program Manager*

Lynn has a master's degree in Health Services Administration from the New School of Social Research in NYC and has coordinated residential and clinical services for people with developmental disabilities for over 18 years. At the Irwin Siegel Agency, she works with providers around the country in the area of risk management and has given presentations nationally. She is responsible for resource development, training, and association support.

### JOHN ROSE

*Vice President of Risk Management*

John has broad experience in the disabilities field and has presented on numerous topics nationwide. John began his career in the field of developmental disabilities as a direct care worker. He has a master's degree in Public Policy. John chairs AAMR's special interest group on Direct Support Professionals and currently serves on the Board of Directors of the National Safety Council. He is also a founding member of the Ontario Association on Developmental Disabilities in Canada. In his current position with the Irwin Siegel Agency, he is responsible for account management and program development.

## Preface

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**WHAT IS PERSON-CENTERED PLANNING** and how can providers respond? This booklet gives an overview of person-centered planning and it looks at the importance of the individual's decisions and ideas, the role of a person's supportive circle of family and friends, and community involvement.

Providers are offered an opportunity to re-examine their role as they support people in reaching for their individual dreams. They also want to address the desires of each consumer, while at the same time meet their responsibilities for the individual's health and safety.

With person-centered planning, new risks may arise. But the consumer, along with a supportive circle of family, friends, and associates, can work to anticipate and address those risks. Balancing consumer choice with provider responsibility will be explored.

People with disabilities want greater freedom and control in their own lives. With the passing of the Americans with Disabilities Act, individuals are finding they can sue for access to services they believe they are entitled to. A positive, proactive, interactive approach to "giving the customer what he/she wants" can avoid costly litigation, as well as provide more desirable services.

Additional information on specific tools for person-centered planning, such as mapping or personal futures planning, can be obtained from the Irwin Siegel Agency. Supporters of person-centered planning promote listening to the individual's dream and providing the supports necessary to make it happen, rather than trying to ensure a particular planning tool is strictly adhered to.

# About ISA

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**FOUNDED IN 1960**, the Irwin Siegel Agency (ISA) has been involved with the disabilities field for over thirty years. ISA is a national program administrator insuring human services providers in 48 states. We have developed an insurance and risk management program designed for agencies servicing people with development disabilities, traumatic brain injury, and other physical or mental disabilities.

ISA offers service and solutions to those who support others. We are actively involved with provider and national associations, such as AAMR and the National Safety Council. Through our involvement, isa has received many awards within the disability field and has been chosen to represent the interests of the developmentally disabled on the National Safety Council Board of Directors. isa has also received the National Safety Council "Distinguished Service to Safety Award."

We are staffed with people who have extensive experience in the field of disabilities and are able to provide timely information through newsletters, resource booklets, videos, training, and seminars. We will also work with safety staff or committees to find solutions for specific concerns. We have an expanding resource library with various items including:

- **Balancing Choice and Provider Liability**
- **Safety for Self-Advocates**
- **Fire Safety for those in Supportive Living Arrangements**
- **Transporting Passengers with Special Needs**
- **Coaching the Van Driver**

# "Here's What I Dream"

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## A Look at Person-Centered Approaches

"In the past, staff made all the decisions. We would like to make our own decisions with staff help, if needed. But not in a controlling way, just being supportive. Really, that's part of the job."

*David Scali, People First*

**PERSON-CENTERED APPROACHES** are based on the individual's dreams and are developed by the individual with assistance, as desired, from family and friends. The focus is on the person's own life wishes and encourages community involvement and support of the person's dream. It is an attempt to break through the traditional continuum of "one size fits all" services to offer more individualized lifestyle and service selection. The foundation for this service delivery change is based on the fundamental belief in the self worth of each individual.

Person-Centered Planning looks to:

- Create services for the individual based on the person's choices, desires, interests, and dreams, rather than fitting the person into a pre-existing service.
- Focus on the person's desires and abilities.
- Design and find supports that build on the capacities of the person and not on deficits.
- Facilitate access to community resources (jobs, housing, education, recreation, and friends).
- Coordinate services around the individual rather than around the needs of the staff or program.
- Recognize the abilities of ordinary citizens (i.e. family, co-workers, and neighbors) to develop relationships, teach skills, and support community participation. It does not require participation by specific interdisciplinary professionals and does not typically include review of professional assessments or case notes.

- Bring together a diverse group of people who know, value, and are committed to supporting the person.
- Work towards supporting the person to attain desired outcomes and usually does not include the development of goals broken down into specific behavioral objectives.

Person-Centered Planning was developed based on a belief that the system of care-giving established for people with developmental disabilities, though well intentioned, was not adequately addressing the fundamental personal values of those served. Below is an outline of the real experiences that people truly value. It was developed by John O'Brien, an advocate for people with developmental disabilities.

### John O'Brien's Five Valued Experiences and Accomplishments

THE 5 VALUED EXPERIENCES	THE 5 VALUED ACCOMPLISHMENTS
1. Sharing ordinary place	1. Supporting community presence <ul style="list-style-type: none"> <li>• What are we doing to promote opportunities to share ordinary places?</li> </ul>
2. Growing in relationships	2. Supporting community participation <ul style="list-style-type: none"> <li>• What are we doing that gets in the way of people forging relationships with ordinary citizens?</li> </ul>
3. Experiencing respect for who I am; having a valued social role.	3. Supporting valued social roles <ul style="list-style-type: none"> <li>• Are we taking direction from each person?</li> <li>• What are we doing to help people experience many possible roles?</li> </ul>
4. Contributing (What am I here for?)	4. Supporting contribution <ul style="list-style-type: none"> <li>• What are we doing to help people discover what they're good at?</li> </ul>
5. Making Choices	5. Supporting opportunities to choose <ul style="list-style-type: none"> <li>• How are we helping people to choose wisely?</li> </ul>

(J. O'Brien, "Self Determination," IMW&A, Columbus, Ohio)

plan and a designation of that person or entity shall be noted in the plan. The provider would regularly review and revise the agreement with the individual, the individual's circle of support and service broker. The individual plan would need to reflect changes in preferred lifestyles, achievement of goals or skills outlined within the plan, or a need to address the plan if any service being provided is unresponsive.

### Regulatory Compliance

More and more, person-centered approaches are becoming required in many states. Of course, it is recommended to be familiar with your state's regulations. In Kansas, for example, the process for planning and implementing person-centered support is clearly delineated. The provider is required to prepare a written person-centered support plan for each person served. The person's preferred lifestyle, including where and with whom a person wants to live, work, socialize, and what other activities they would like to participate in should be included.

Many states support personal plans which are developed only after consultation with the person, the person's legal guardian, if one has been appointed; and other individuals from the person's support network, as the person or the person's guardian chooses. Personal preferences and interests must also be addressed.

### In Conclusion

John Rose stated in his article on balancing choice and provider liability, "The trend toward consumer driven support services will require a re-thinking of how to provide individualized services, and to truly support each person's goals and aspirations."

As we learn to listen and act on the desires and ambitions of each individual, the services we provide will truly become more consumer driven. We can support each person who requests our assistance in achieving his own dreams and aspirations.

- A description of when it may be necessary to limit a preferred lifestyle through your service delivery system because of imminent, significant danger to the person's health, safety, or welfare based on an assessment of the person's ability to make an informed choice.

As noted by John Rose in his article on "Balancing Choice and Provider Liability," the following components are needed in order to make an informed choice:

- **KNOWLEDGE—OPTIONS/EXPERIENCE/PREFERENCE:** Has the individual had the experience to be able to make an informed decision?
- **BENEFITS/RISKS—DEGREE OF HARM, ACCEPTANCE OF RESPONSIBILITY:** Does the individual recognize and accept responsibility for risks involved in normal activities?
- **VOLUNTEERISM—ABILITY TO SAY NO/FREE CHOICE:** Can the individual express his choices?
- **VALUES—INDIVIDUAL:** Are the values related to the decision those of the individual, or is someone else pushing their own values on the individual?

Providers should also consider documenting:

- The person's history of decision-making, including previous experience and the ability to learn from the natural negative consequences of poor decision making.
- The long and short term consequences that might result to the person if the person makes a poor decision.
- The possible long and short term effects that might result to the person if the provider limits or prohibits the person from making a choice.
- The safeguards available to protect the person's safety and rights in each context of choices.
- Where individualized plans are required, note who is responsible for the development of a person's individual plan. The person, guardian, if one has been appointed, a member of the person's support network, an independent service broker, or a provider shall take the lead coordination role in the preparation of the

## Tools for Person-Centered Planning

There are a number of person-centered planning tools that have been developed. Some of these include:

- **PATH (Planning Alternate Tomorrows with Hope) by Forest/Pearpoint/O'Brien**  
PATH is a systematic creative planning tool that begins by creating a vision, then specifies actions to get moving on the journey to that desirable future.
- **MAPS (Making Action Plans) by Forest/Pearpoint**  
MAPS is a powerful way of creating a holistic portrait and of collecting real information about a person, a family, or an organization. MAPS is a process for people or organizations to share their stories and begin making changes that will lead to closer relationships with vulnerable persons, families, or organizations.
- **Essential Lifestyle Planning by Michael Smull.** Michael Smull writes on support coordination using a simple, direct, common-sense approach.
- **Building Community by Schwartz/McKnight**
- **Personal Futures Planning by Beth Mount through Graphic Futures.** She has written of ways to listen to hope, deepen relationships, recognize and develop preferences, explore community opportunities, develop a vision of a possible future, and to consider what may need to be learned.

In any person-centered planning, the person should have the authority to choose who will facilitate their planning meeting. The facilitator of the planning meeting is a listener who encourages brain storming and creative planning. They can be a family member, friend, a professional from a service provider, or an independent service broker.

Each of the person-centered planning methods are formats for creative listening, thinking, envisioning, and planning. They are not intended to create a new standard set of procedures, but rather, are used to visualize thoughtful and exciting ideas for enhancing one's lifestyle.

## Circles of Support

A circle of support is based on a model of a group of people gathering around a person who has become excluded or isolated. The focus of the group is to find and create ways for the person to participate in his/her community. The participation is structured around the talents that this person wants to contribute to the community. The circle discovers the person's gifts by listening to his/her dream and personal story. Circles usually start around the needs of one individual, but over time, reciprocal relationships can develop.

The circle of support can be made up of family, peers, neighbors, co-workers, teachers, or caregivers. A circle of support can include people who are very close, friends and allies who may not be as close but are still good friends, acquaintances from work or school who care, and people who are paid to be in the life of the individual to provide a service. The individual chooses the people who will be in his or her circle of support.

The people in circles of support listen to the person and help identify and support the dreams of the person. They are involved in the planning steps to reach those dreams. It is likely that a greater quality of life can result with a more developed circle of support.

## Community

Person centered approaches often look to ways of enhancing a person's connection to his or her community. Development of friendships, relationships, and associations are carefully considered. Growth of ordinary community interaction is encouraged. After a person expresses his or her interests and wishes, steps are mapped out to involve the person with community activities they would enjoy. For instance, if the person likes animals, perhaps they would be interested in and capable of doing some volunteer work at a kennel or animal shelter. Someone who loves music may be able to participate in some way with the community chorus. Visiting the local grocer and picking up their own favorite items may also be part of a conscious plan to build a network of contacts with the community. Community building can

- Establishes a Safety Committee made up of self-advocates, family, direct service professionals, service coordinators, along with executive staff support.

## Individual Risk Management Process

- **IDENTIFICATION** – Know the individual's abilities, desires, and the potential risk. Identify the level of risk involved in the activity in general, and the amount of knowledge the individual has about the activity and its associated risk.
- **ASSESSMENT** – Evaluate the choices. Consider the consequences of choices before taking action. Involve the individual in the process. Determine the level of monitoring or support needed.
- **IMPLEMENTATION** – Select the 'best,' choice. Make a plan and implement it.
- **MONITOR** – Monitor to ensure safety and individual satisfaction.

*Based on John Rose's, "Balancing Choice and Provider Liability," Irwin Siegel Agency)*

Individualized service contracts and waivers may be in order. An agreement of responsibilities of the provider and the consumer will need to be individually specified.

A primary service provider would probably want to document:

- A list of supports needed to live the lifestyle desired and those that the provider will provide or coordinate.
- How opportunities for choice will be provided.
- Provision of any necessary support and training to enhance the person's ability to be able to indicate their preferences.
- Assistance offered to the person or the person's guardian to understand any known, possible, or foreseeable negative consequences of choices the person might make and what may involve risk to that person.

**8** The person is satisfied with his or her activities, supports, and services.

- The person expresses satisfaction with his or her relationships, home, and daily routine.
- Areas of dissatisfaction result in tangible changes in the person's life situation.

*(Hallmarks for a Person-Centered Approach, NYS-OMRDD)*

## **A Person-Centered Agency**

- Has a clear vision and mission, and lives its mission.
- Listens to people.
- Ensures a culture of caring.
- Supports pockets of innovation.
- Recognizes and rewards 'Best Practices.'
- Limits program size, hierarchy.
- Trains, supports, and values Direct-Support Professionals.
- Thinks locally, observes globally.
- Develops relationships with the community through education and coordination.
- Stands behind efforts to give consumers greater control of fiscal supports and choice of provider.

## **Quality Component**

Providers must support individual choice while at the same time manage risk. An agency wide cultural shift will be needed to:

- Keep the individuals desires first.
- Provide appropriate individualized supports to obtain their dreams.
- Arrange "stepping stone" opportunities towards the persons goals when warranted.
- Ensure safety, courtesy, and individual rights.

involve participation in religious groups, civic events, fitness clubs, etc. Assistance in friendship building is also provided as desired by the individual. Associations at school and work are also considered when looking for opportunities to build community.

## **Consumer Driven Supports**

Consumers, along with their circle of support, decide how they want to live and what they want to do and learn. Service providers are contracted to provide desired services. Providers follow the consumers lead. Services that the consumer wants are those which are provided, to the greatest extent possible. In a self-determination model, given a limited amount of funding for services, the consumer chooses where that money will be spent. They may receive assistance from a service broker or fiscal intermediary.

## **A Person-Centered Approach**

Many agencies have found the process to be exciting but difficult to implement, given fiscal constraints, current limits on control of resources, resistance to systematic change and control, and individual circumstances. While proponents emphasize the need for a "Why not, let's do it!" attitude, some providers have chosen to use what they can of the person-centered process to keep the individual's desires first. Programs want to incorporate a person-centered approach, if not "pure" person-centered planning, in their planning and delivery of activities, supports, and services. Families and individuals should be aware that person-centered approaches may not guarantee attainment of all the persons goals, because of funding or other resource restrictions. Plans are made given the limited resources available.

A positive, realistic approach in moving towards the person's desired goals is often used. Reviewing what it is about the life dream that is appealing to the individual may reveal a simpler or practical goal that is desired and can be met. Providers need to be open to new ideas for service delivery and resist claiming "it won't work" before re-thinking some alternatives.

The following are "Hallmarks for a Person-Centered Approach," as defined by Schwartz, Warren, and Rossi, from the New York State Office of Mental Retardation and Developmental Disabilities:

- 1** The person's activities, services, and supports are based upon his or her dreams, interests, preferences, strengths, and capacities.
  - The person's dreams, interests, preferences, strengths, and capacities are explicitly acknowledged and drive activities, services and supports.
  - Services and supports are individualized and do not rely solely on pre-existing models.
  - Supports and services have outcomes selected by the person which are meaningful and functional.
  - The person achieves personal goals.
- 2** The person and people important to him or her are included in lifestyle planning and have the opportunity to exercise control and make informed decisions.
  - The person and advocates participate in planning and discussions where decisions are made.
  - A diverse group of people, invited by the person, assist in planning and decision-making.
- 3** The person has meaningful choices, with decisions based on his or her experiences.
  - The person has opportunities to experience alternatives before making choices.
  - The person makes life-defining choices related to home, work, and relationships.
  - Opportunities for decision-making are part of the person's everyday routine.
  - The person decides how to use his or her free time.

- 4** The person uses, when possible, natural and community supports.
  - With the person's consent, the support of family members, neighbors, and co-workers is encouraged.
  - The person makes use of typical community and generic resources whenever possible.
- 5** Activities, supports, and services foster skills to achieve personal relationships, community inclusion, dignity, and respect.
  - The person has a presence in a variety of typical community places. Segregated services and locations are minimized.
  - The person has friends and the opportunity to form other natural community relationships.
  - The person can access community-based housing and work, if desired.
  - The person has the opportunity to be a contributing member of the community.
- 6** The person's opportunities and experiences are maximized and flexibility is enhanced within existing regulatory and funding constraints.
  - Funding of supports and services is responsive to personal needs and desires, not the reverse.
  - When funding constraints require supports to be prioritized or limited, the person or advocates make the decisions.
  - The person has appropriate control over available economic resources.
- 7** Planning is collaborative, recurring, and involves an ongoing commitment to the person.
  - Planning activities occur periodically and routinely. Lifestyle decisions are revisited.
  - A group of people who know, value, and are committed to serving the person remain involved.