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ABSTRACT

These two newsletter special issues focus on personal futures planning (PFP) for people with deaf blindness, with emphasis on technical assistance activities involved in implementing a PFP program. PFP guides a team through three phases of activities: (1) developing a "circle of support" for an individual with deaf blindness; (2) describing a desirable future for the individual; and (3) developing and implementing an "action plan." PFP is seen as a complement to Individualized Education Programs and Individual Written Rehabilitation Plans. Two training efforts of the Helen Keller National Center/Technical Assistance Center are described. The newsletter also compares the old system-centered approach with the person-centered PFP approach; explains the components of PFP maps; offers several parents' perspectives on PFP; provides a sample PFP map, a sample action plan, and a list of PFP resources; and examines PFP from the perspective of an individual with multiple disabilities. (DB)

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Helen Keller National Center

HK News

TAC

Technical Assistance Center

Volume 6, Number 2

Winter-Spring 1992-1993

Supporting the Transition of Youth with Deaf-Blindness

Over the past five years, personal futures planning (PFP) has captured the imagination of families and service providers. PFP is a person-centered planning approach seeking to identify and mobilize formal and informal supports around the needs of an individual with a severe disability. It has been used successfully to create housing, employment, leisure, friendships, and other life-style supports for young adults with deaf-blindness in many areas across the United States.

PFP can be "a tool for fostering new ways of thinking" (Mount & Zwernik, 1988) about people with deaf-blindness. It is not simply another type of service plan; it is a process, an on-going problem-solving process, involving a committed team of family members, friends, and service providers. The process is characterized by planning that describes capacities and opportunities in people and environments. It is a visionary and future-oriented planning process. It uses the commitment, motivation, creativity, and initiative of people who live with the individual and his or her problems and dreams every day.

PFP guides a team through three phases of activities: 1) developing a "circle of support" for an individual with deaf-blindness; 2) describing a desirable future for the individual; and 3) developing and implementing an "action plan" with resources, commitments, activities, and timelines needed to bring about a desired future vision for the individual with deaf-blindness.

Because it is a new way of thinking, and because it requires commitment and a great deal of time and energy, PFP works well for some individuals with deaf-blindness, some families, and some service providers. But it is not for everyone. Nor is it an alternative to an IEP (Individualized Education Program) or IWRP (Individual Written Rehabilitation Plan). Rather, it complements the goals and objectives of these more formal plans by enhancing the supports in a person's life.

The purpose of this newsletter is to describe the parent-professional technical assistance activities that introduced PFP into the lives of many individuals with deaf-blindness. It is also a description and a celebration of the life-style accomplishments of some of the most committed and successful "circles of support".

.....
JANE M. EVERSON is HKNC-TAC's Project Director.

PERSONAL FUTURES PLANNING



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The Technical Assistance Center of the Helen Keller National Center (HKNC-TAC) is a national technical assistance center funded by the United States Department of Education, Office of Special Education Programs, Agreement #HO25E90001.

HKNC-TAC's purpose is to provide national training and technical assistance to education programs and adult agencies providing school-to-adult-life transition services to youth with deaf-blindness.

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SPOTLIGHT ON HKNC-TAC PFP TRAINING

During the past 24 months, HKNC-TAC sponsored two national parent-professional workshops on personal futures planning. The workshops, designed and conducted by Dr. Beth Mount, (of Graphic Futures, New York, NY.) were attended by parents and professionals interested in facilitating a person-centered planning process on behalf of someone who is deaf-blind. The goal of the training was to provide participants with information on the values and methods of the PFP process and to offer an opportunity for a team to work collaboratively in developing a personal futures plan for an individual with deaf-blindness.

HKNC-TAC invited teams from 25 states to attend the workshops. Teams always consisted of a parent or family member and one to two professionals. Very often one of the professionals was part of the HKNC's Field Staff or Affiliate Network. Whenever possible the third team member was a local service provider working with the individual with deaf-blindness.

During the workshops, the teams emerged as the nucleus or core of a "circle of friends" to be further expanded upon returning home. Participants learned that membership in this circle is always voluntary and not necessarily dependent on a title or position within an agency. On the contrary, the circle is first and foremost a gathering of people who know and care about the focus person, the individual with deaf-blindness, and who are willing to make a commitment to enhancing this person's life.

PFP uses meeting frameworks and maps to aide the planning process. Information is mapped using colors, symbols and words on large pieces of chart paper. The color-coding of information is extremely useful in identifying important patterns, barriers and opportunities that exist in the life of the focus person. There are four basic meeting frameworks in the PFP process:

1. An initial meeting to explore commitment and who might be involved in the circle;
2. One or two meetings to generate a "personal profile". A personal profile describes the person's life story by using the following maps:

Relationships	Hopes & Fears	Places
Choices	Background	Health
Preferences	Respect	Dreams/Vision
Communication	Others (invented by the group)	
3. Profile meetings lay the groundwork for one or two planning meetings. During these meetings an action plan is written and people make commitments for its implementation.
4. Follow-along meetings are held as frequently as necessary to help maintain commitment and attention to the plan.

The response to these two training efforts has been overwhelmingly positive. Parents are delighted for the opportunity to focus on their child's capacities and talents and not just deficiencies and limitations. One parent, upon completing the training, commented that it was "a dream come true!"

.....
KATHLEEN MCNULTY, Assistant Project Director, directs all HKNC-TAC's parent and family activities.

HOW DOES PFP DESCRIBE PEOPLE?

Person-centered planning, which PFP utilizes, challenges us to value each person as unique, with many gifts and possibilities; to find ways to discover our common experience and work together to build a life where these gifts can be enhanced and shared with others. This "new way of thinking about people" is contrasted with the "old way" -- the system-centered description, below.

SYSTEM-CENTERED

- Focus on labels
- Emphasis on deficits & needs
- Invest in standardized testing & assessments
- Depend on professionals to make judgements
- Generate written reports
- See person in the context of the human service systems
- Distance person by emphasizing differences

PERSON-CENTERED

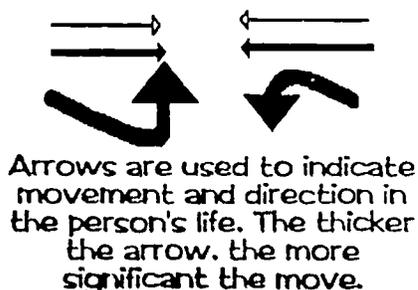
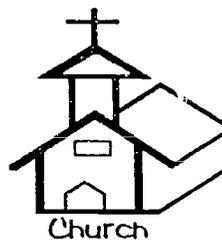
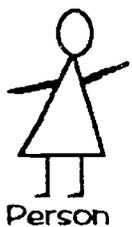
- See people first
- Search for capacities & gifts
- Spend time getting to know the person
- Depend on person, family and direct service workers to build good descriptions
- Gather "folklore" from people who know the person well
- See person in the context of his or her local community
- Bring people together by the discovery of common experiences

The *system-centered approach emphasizes deficiency*, summarizing the dominant view from written evaluations by specialists who describe how the person is *different* from other people. The contrasting *person-centered alternative seeks to emphasize the person's interests, gifts, and contributions*, which will have a significant impact on the person's future.

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(This article is adapted from Mount, 1988)

Basic PFP Symbols



4



PFP MAPS

An integral part of personal futures planning is the development of "maps", which are graphic representations of information about different aspects of a person's life. Each map is created using information about the focus person contributed by those who know him or her best. This chart describes commonly used map topics and their use.

TOPIC	PURPOSE	HELPS ILLUSTRATE
Relationships	Identify personal support and assistance.	Most Important people in focus person's life. People interested in planning together over time. Opportunities for building relationships.
Places	Describe the pattern of daily life.	How focus person spends time. Community & segregated settings used. Existing opportunities for building community.
Background	Understand life experiences of focus person and family.	Positive experiences from past on which to build. Appreciation of traumas, loss, grief. Celebration of accomplishments. Opportunities in the present as a result of past.
Communication/ Interaction	Discover capacity to express and receive information.	Focus person's individualized communication methods that might otherwise be overlooked. Who interacts with person, during what activities, and examples of vocabulary used.
	Discover capabilities to build upon and conditions to avoid.	Patterns in gifts, potential, interest & unique contributions of focus person. Patterns in conditions that block or challenge development opportunities to build on in future.
Dreams for the future	Explore desires & dreams for future life.	Experiences the focus person wants to have. Dreams for a home, a job, community life, and personal life.
Hopes and Fears	Describe how people feel about the future.	How life looks to focus person & those close. How optimistic or pessimistic people feel about their desires. How obstacles & fears compare to the hopes & opportunities they see.
Choices	Describe personal autonomy & needs for assistance	Degree focus person has control over life decisions and personal care. Degree other people make decisions for person & must help person with daily routines.
Health issues	Describe conditions that promote or threaten health of the person.	Real limitation imposed by health concerns. Conditions & routines that assure good health.
Respect	Identify barriers to community acceptance.	Personal characteristics that cause rejection. Personal characteristics, behaviors & social roles that will help person gain respect.

Parent's Perspectives on Personal Futures Planning

The privilege of attending the first HKNC-TAC training session by Dr. Beth Mount was so exciting! PFP: person-centered focus, looking at a person's capacities, personal preferences, enabling and creating opportunities for positive growth and enrichment. A process through which our dreams for enrichment of our daughter, Sara's life can be achieved! No more listing deficiencies, behaviors, deficits, fitting into a pre-existing slot in a program. This process will show the world what a super, sweet, happy, productive person Sara can be, when given the opportunities to have her choices, her preferences, her gifts and her skills become the focus of her family and care givers. The strategies and process had been developed, successfully tested. And here it was--to take home and implement. Utopia at last! Even beyond Utopia! Kathy McNulty offered to be facilitator for Sara's PFP. I didn't need a plane to fly home from the workshop in Atlanta!

Our first meeting to do background and relationship maps was very successful. Sara's communication skills and attention level prevented her participation in discussion. Therefore we needed help from those folks who know her very well. Direct care staff from her residential and day programs participated with Kathy and myself and the process was started and working well.

Sara's brothers, sisters, their spouses and her godmother were anxious to become involved in the process. We have had some wonderful meetings with all of our family and on most occasions, a staff person from her residence has attended. We continue to invite significant caretakers and administrators in Sara's life.

The maps we have developed have helped family members to better understand Sara's world and how they can more fully participate in enriching her life as well as their own and their children's relationship with her. The formalized meetings that we have had with Kathy facilitating from a neutral point of view have proved a marvelous vehicle for bringing Sara more prominently into her sibling's lives. Each of them attended college away from home, four of five have lived out of state for a number of years, are married and have children. Aside from occasional family gatherings, their contacts with and updates on Sara were principally through "Mom". At the PFP meetings they agreed to do various things to help accomplish Sara's dream for the future. As these tasks are completed, they are closer and more involved with their sister.

And best of all, Sara's life has surely been enriched--and we've only just begun. Most gratifying!

.....
MARY O DONNELL, from New Jersey

Persona. Futures Planning has really been a positive experience for us. Through this process we have developed relationships with people in many areas of Jenni's life. More importantly, those people now know the "real" Jenni. She is no longer a name and number but a person who has likes and dislikes, who can make choices and function in the community. Now they look for ways to adapt the environment to Jenni as opposed to the old way of fitting her into the system.

Membership has changed since the first meeting. We have about the same number of participants but the faces are different. Unfortunately family members have been reticent to become involved. Our current PFP group includes: Jenni's mom and step-father; a representative from the intermediate school district; a teacher/consultant specializing in deaf-blindness, who knew Jenni as a young child; a counselor involved with Jenni's work experience; a facilitator, and Jenni, when she feels comfortable attending. Some other people came initially but did not remain in the group. We are inviting a work-study coordinator from Jenni's neighborhood school, a high school teacher for the hearing impaired and a respite care worker to our next meeting.

Meetings occur about every four months and are held around 4PM on a weekday in our home. Dinner and munchies are usually provided which adds to the informal nature of the meetings. We begin each meeting by reviewing the notes from the last meeting, especially the tasks which were assigned to each member. Each participant gets an opportunity to update the group. Our focus since completing the map work revolves around the Vision for the Future map, since this is the driving force of our planning, a future for Jenni that will meet her wants and needs.

Many changes have occurred since we began the PFP for Jenni last year. She now volunteers at the local Community House two days a week after school. Currently she is doing clerical activities but the facility has child care, kitchen and cleaning activities that Jenni may explore in the future. In her vocational experience, Jenni participated in a trial session in a restaurant setting at her request. We have also visited other possible vocational settings that include food preparation.

Other improvements have occurred as a result of PFP. People in the group have a better understanding of Jenni's likes and dislikes and of her accomplishments. We all think very positively when we talk about Jenni. We don't use "can't" or "won't

Continued on following page

Perspectives, Continued

work". As a group we have learned many things about Jenni that can affect her quality of life if they are ignored:

- ☑ Jenni needs time to get used to people.
- ☑ Jenni stores information until she needs it.
- ☑ Jenni likes working and is proud of her work.
- ☑ Jenni needs to stay with an activity for an extended period to know what to expect.

There are areas of Jenni's plan that need more work. Our future focus will include the following issues:

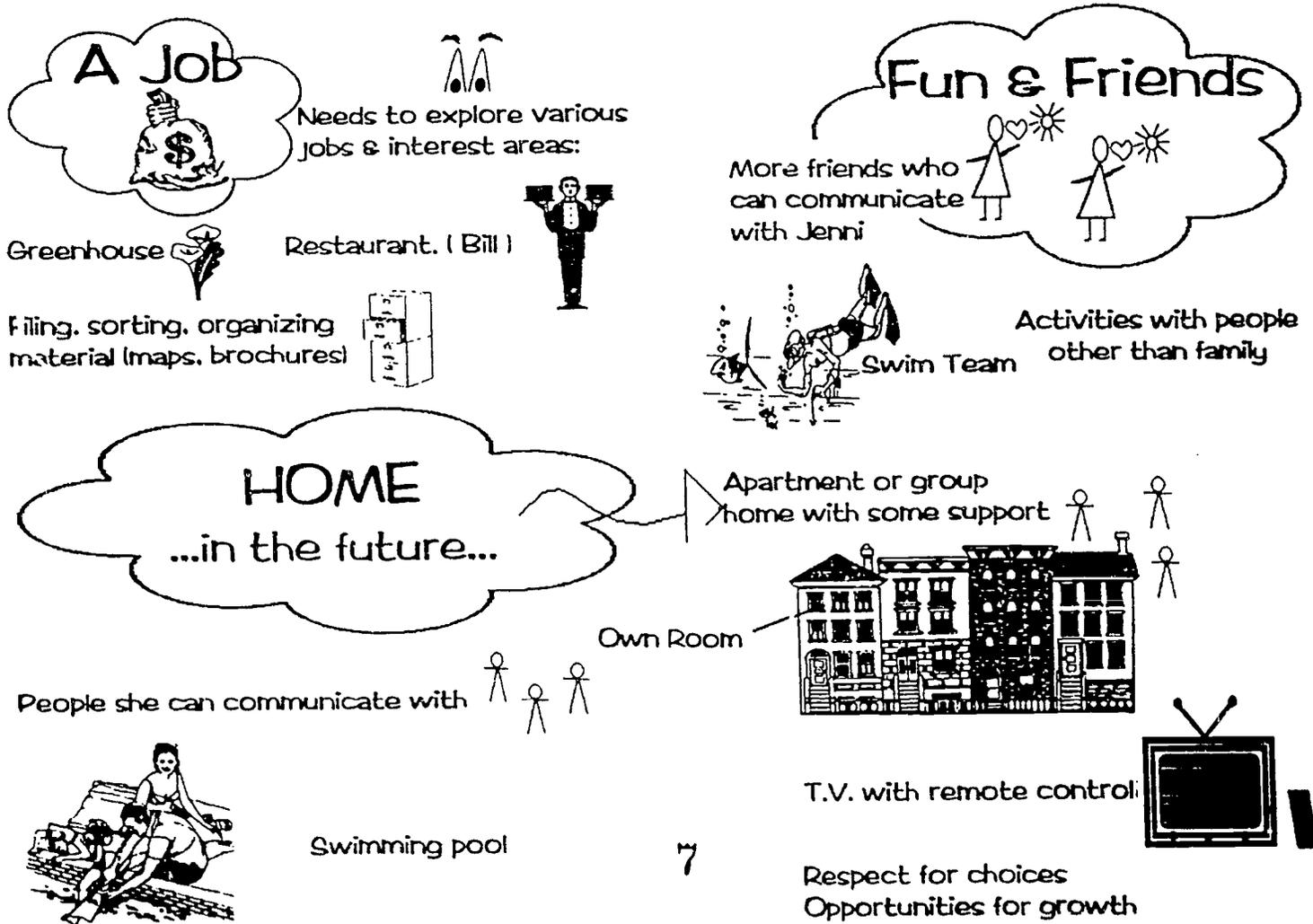
- ☑ Include more community-based instruction into her mobility training.
- ☑ Social opportunities are limited. Jenni is lonely for other deaf persons but the language skills of the local deaf community are too sophisticated for her.

- ☑ Jenni needs a variety of work experiences.
- ☑ Peer tutoring will be the topic for our next meeting. One member has information and we plan to brainstorm how this could benefit Jenni.
- ☑ Living options remain an important area of concern.

When we first began personal futures planning last year I did not believe that professionals would be willing to attend such a meeting, after work on their own time. And I certainly didn't think that they would continue coming when they realized that this would be an ongoing group. But I forgot one important point as I was minimizing their involvement. They too were benefitting from the experience!

.....
 MARY LOU GUISENGER, from Michigan

Vision of the Future Jenni's Map



More Parent's Perspectives

Thanks to Personal Futures Planning, our daughter's life has improved dramatically in the past two years. At that time the institution which had been Mila's residence for 10 years decided it could not provide the level of care she required. Mila's increasing frustration with her profound deafness, her blindness, (and who knows what else), had created challenging behavior problems, which would be difficult for any program. We had been so grateful to find an institution that was able to deal with her problems for a few years. But now we felt desperate and totally overwhelmed. We needed to find another residence for her. We don't know what we would have done without the great assistance of the Helen Keller National Center-Technical Assistance Center program associate in our area, Mike McCarthy, who called us when her heard of our daughter's plight.

Besides helping to bring several agencies to work cooperatively on our daughter's behalf, Mike called in Pat Puckett from Atlanta, Georgia to come to our home in Columbia, Missouri to facilitate Mila's first personal futures planning meeting. It was attended by family, friends and representatives from the various agencies. Ms. Pucket was trained by Beth Mount, who developed the PFP process. Since then, we have had many PFP meetings which resulted in Mila's new home, which she shares with another young woman.

What a wonderful way of looking at people this is: it focuses on an individual's strengths while still recognizing and accepting those areas that might need extra support. This process encourages fulfillment of personal dreams and desires, rather than seeing what niche, if any, might be available to try to fit into. Our daughter's present happiness in her new home, (a supported living program) and the subsiding of her severe behavior problems is a clear tribute to the philosophy and power of personal futures planning.

Happily, we are out of the desperate situation that seemed to characterize most of our daughter's life. That does not stop us from dreaming about what our daughter's dream might be. Using Mila's PFP meetings with their combination of people, time, commitment, patience and extraordinary efforts, we are continuing to help Mila's dreams come true and our own as well.

.....
MARIA AND KEN PINCKNEY, from Missouri.

MARK'S PFP EXPERIENCE

I started planning my future two years ago. Since that time, some of my dreams have come true. It wasn't always easy, but I had the support of many people including the governor of my state! Up until last year, I was living at my mother's house or, at times, a state mental institution. With the help of a friend, I wrote to the governor to tell him that I wanted a place to live; that my home and the state institution were the wrong places. My dream was to live on my own, with staff helping me, especially at night, when my eyesight is the worst. I also wanted to get a full time job in a restaurant and have a girlfriend.

My dreams are beginning to come true for me. I now live in a house with one roommate. There is staff at my home all day and night. I am learning to live more independently with their help (taking my medications, getting up on time, paying bills, shopping, cooking). I also choose what recreation activities I do. I have joined the YMCA and play basketball and lift weights. I competed in both soccer and baseball and won a baseball trophy which I am very proud of. I go out to Tiger baseball games, and have tried go-carts, miniature golf and hiking. I really like doing things because when I'm bored I become frustrated. As you can see, I have little time to be bored! Right now, I am really excited because I will vote for the first time this year too.

Even though all my dreams have not happened yet I have people around me that are helping me to get what I want, and teach me what I need to know to get it. The best thing that has happened to me is I have a lot more freedom.

.....
Mark Bishop, Tacoma, Washington

PFP for Mark included a variety of people some of whom changed over time and according to need. The key people who helped Mark achieve parts of his dream included his mother, his teacher and other educators, a representative from the Department of Developmental Disabilities, a friend, representatives from a ARC (who began the PFP process), a transition specialist and (as necessary) representatives from the state mental institution.

Mark developed his future plan with the help of a facilitator. The team was there to listen and help him achieve his plan. Mark was the focus person and his input was highly valued and all his remarks were noted during the mapping process. This was markedly different from Mark's and his mom's experience in the past.

Continued on following page

Mark's PFP Experience, Continued

The initial meeting centered around a family crisis, resulting in Mark's need for an out-of-home placement. However, no community alternatives were available and the only option was a state institution. This is when mom wrote legislators and Mark wrote a letter to the governor (with the help of a friend on the team) to encourage rapid change. It worked. Mark was soon placed in the community as a result of the team's actions. Prior to the move Mark and the team talked about school, work, what neighborhood he wanted to live in, which support services he wanted to insure his success and provide him with the opportunity to meet his ultimate goal of independence. Mark chose his own house. He has made decisions about school. He has also found that medications, counseling and the lack of boredom reduced his frustration and anger.

PFP has empowered Mark. It has given him choices and allowed him to realize some of his dreams. He has seen what action he and others can take to effect change. The original PFP was done with a facilitator from the ARC; now that will change. Mark and a friend have emerged as the group's facilitators. Mark's PFP has been successful -- because all were willing "to go the distance" for him.

.....
 JoAnn Enos (a member of Mark's PFP team)

MARK BISHOP is in his early 20's and lives in Tacoma, Washington. **JOANN ENOS**, an HKNC-TAC Program Associate in Seattle, is a friend of Mark.

Mark's Dream Map and Action Plan can be found on pages 9 and 10 of this Newsletter.



MARK WITH HIS BASEBALL TROPHY

"A pile of rocks ceases to be a rock pile when somebody contemplates it with the idea of a cathedral in mind"
Saint Exupery

25 Lessons for Life

1. There is no free lunch. Don't feel entitled to anything you don't sweat and struggle for.
2. Set goals and work quietly and systematically toward them.
3. Assign yourself.
4. Never work just for money or power. They won't save your soul or build a decent family or help you sleep at night.
5. Don't be afraid of taking risks or being criticized.
6. Take parenting and family life seriously and insist that those who represent you do.
7. Be serious.
8. Be honest
9. Remember and help america remember that the fellowship of human beings is more important than the fellowship of race, class, and gender in a democratic society.
10. Don't mistake style for substance.
11. Never give up!
12. Be confident that you can make a difference.
13. Don't ever stop learning and improving your mind.
14. Don't be afraid of hard work or teaching your children to work.
15. Slow down and live.
16. Choose your friends carefully.
17. Be a can-do, will-try person.
18. Try to live in the present.
19. Use your political and economic power for the community and others less fortunate.
20. Listen for "the sound of the genuine" within yourself and others.
21. You are in charge of your own attitude.
22. Remember your roots, your history, and the forbears' shoulders on which you stand.
23. Be reliable and faithful.
24. Always remember that you are never alone.
25. If the child is safe every one is safe.

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 Adapted from *The Measure of Our Success: A Letter to My Children and Yours*
 by Marian Wright Edleman

Mark's Dreams, Desires and Possibilities



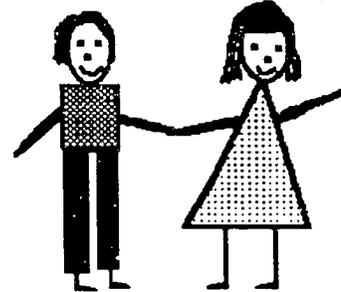
Full-Time Employment

Make money
Physical work
Not too many people
Not too much noise



Social

Have a girl friend
and a relationship



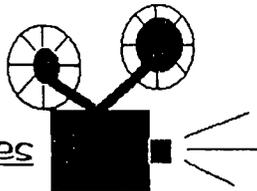
Residential

Live in house or apartment in
Tacoma/Pt. Defiance area
Live with one other person
Supervision
Does not want to live alone

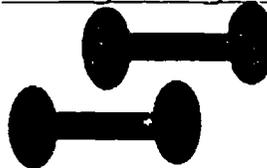
Leisure

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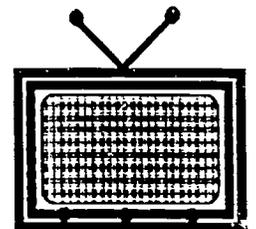
Movies



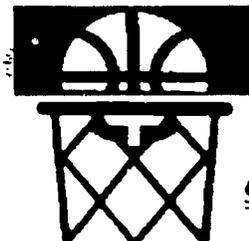
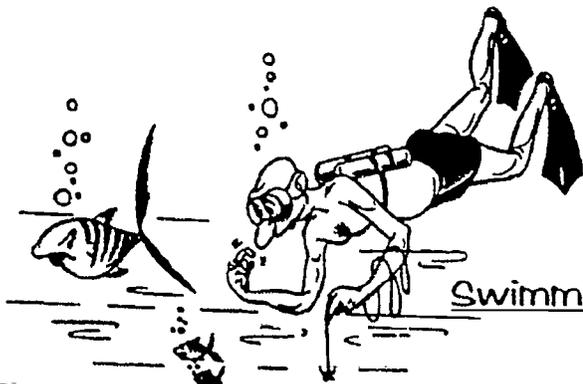
Lifting Weights



T.V.

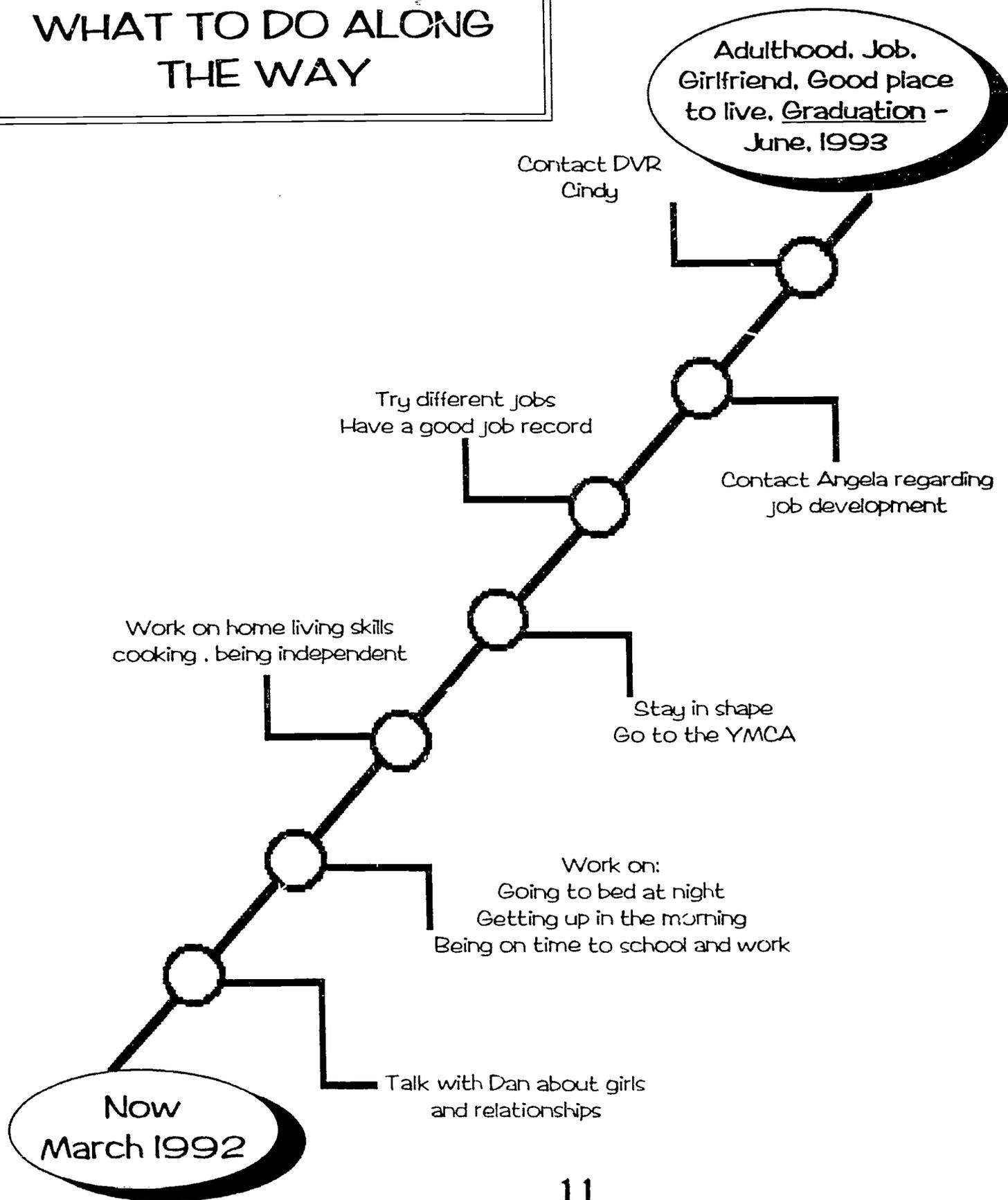


Swimming



Special Olympics

MARK'S ACTION PLAN:
HOW TO GET THERE
WHAT TO DO ALONG
THE WAY



Spread the Word

Attention Rehabilitation Counselors! HKNC is offering a series of workshops for rehab counselors, from RSA Regions II and III only. Topics and dates scheduled are:

Orientation to Deaf-Blindness

February 8-11, 1993

Supported Employment and Deaf-Blindness

April 12-15, 1993

Community Living and Deaf-Blindness

June 7-10, 1993

Orientation to Deaf-Blindness

November 15-18, 1993

For more information, write or call Sister Bernadette Wynne at HKNC.

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Save the Date: Helen Keller National Center and HKNC-TAC and Virginia Commonwealth University - RRTC are planning a **Teleconference on Supported Employment for Individuals with Deaf-Blindness**. It is to be telecast nationally on September 15, 1993. More information will be provided in upcoming TAC newsletters.

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The William A. Thomas Braille Book Store, believed to be the first such retail store in the nation, has been opened by Braille International, Inc., a non-profit organization in Florida. The books, which are sold at cost, are priced from 72 cents to more than \$300. Free catalogues of the titles offered at the book store are available in print or braille, and books may be ordered by mail. For more information or to receive a free catalogue,

call: 1(800) 336-3142

write: 3142 S.E. Jay Street
Stuart FL 34997

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The RP Foundation Fighting Blindness is a research foundation dedicated to finding a cure for inherited diseases like retinitis pigmentosa (RP), Usher syndrome and some forms of macular degeneration. They have published a useful, clearly-written booklet, *Information About Usher Syndrome*, which not only describes this cause of deaf-blindness but also includes lists of service and resource organizations regarding visual impairments and deaf-blindness. These are free with a limited number available.

Also of interest is their Usher Syndrome Self-Help Network. Through it, individuals who have Usher syndrome and their families can interact on a telephone and letter network sharing, ideas, coping strategies, resources and experiences.

To receive a copy of the RP Foundation's Usher syndrome booklet, or to find out more about the self-help network and to learn about their other activities and publications, contact:

National Retinitis Pigmentosa Foundation, Inc.
d/b/a RP Foundation Fighting Blindness
140 Mt. Royal Avenue, 4th floor
Baltimore, MD 21217
1-(800) 683-5535 (410) 225-9400
TDD: (410) 225-9409 FAX: (410) 225-3936

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"That All May Worship", a new handbook to assist congregations, denominational groups, and seminaries to welcome people with disabilities into all aspects of worship and religious life, is now available from The National Organization on Disability. Single copies of this handbook are available at no cost. Additional copies may be purchased by sending a minimum contribution of \$6.00 per copy payable to N.O.D. You can obtain the handbook by writing to:

Religion and Disability Program
National Organization on Disability
910 16th Street, N.W., Suite 600
Washington, D.C. 20006

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New directory available: **Directory of Agencies Servicing Individuals who are Deaf-Blind** published by HKNC lists alphabetically by state programs serving individuals with deaf-blindness nationwide. This resource for parents and professionals includes eligibility requirements, major services, geographical service area, funding sources and other information. It is compiled from an extensive survey completed recently by HKNC. The Directory's ringed-binder permits the addition of updated material which will be available periodically for a minimal fee. To order: Send check or money order for \$25.00 to:

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111 Middle Neck Road
Sands Point, New York 11050-1299

"When one door closes, another opens; but we often look so long and so regretfully upon the closed door that we do not see the one which has opened for us."

Alexander Graham Bell

COMPONENTS OF AN EFFECTIVE PFP PROCESS

- People begin with a clear and shared appreciation of the gifts and capacities of the focus person.
- Committed people develop a common understanding of a specific positive future: a common dream.
- Committed people agree to meet regularly to brainstorm and make commitments to act. These people are often those who spend a lot of time with the person or have known the person for a long time.
- The group includes at least one person--a family member, advocate, community member, staff person, advocate, or the person who is the focus of the planning--who is champion of the dream. This person makes extraordinary efforts to bring the dream into reality.
- At least one agency or community organization is committed to supporting the implementation of the plan.

(Mount, 1990)

RESOURCES FOR PERSONAL FUTURES PLANNING

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Korten, David. "*People-Centered Development: Toward a Framework*". In Korten and Klauss (Eds.), **People-Centered Development: Contributions Toward Theory and Planning Frameworks.** West Hartford: Kumarian Press.

Mount, B. Ducharme, G. and Beeman, P. (1991). **Person-Centered Development: A Journey in Learning to Listen to People with Disabilities.** Available from Communitas, Inc., P.O. Box 374, Manchester, CT 06040.

Mount, B. & Zwenik, K. (1988). **It's Never Too Early. It's Never Too Late. A Booklet About Personal Futures Planning: For Persons with Developmental Disabilities, Their Families and Friends, Case Managers, Service Providers and Advocates.** Metropolitan Council's DD Case Management Project, 230 East Fifth St., St. Paul, Minnesota 55101.

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O'Connor, M. (1988). **The Gift of Hospitality: Opening the Doors of Community Life to People with Disabilities.** Chicago: Center for Urban Affairs and Policy Research, Northwestern University and Illinois Department of Rehabilitation Services.

Perske, R. (1988). **Circle of Friends.** Nashville, TN: Abdingdon Press.

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GOOD NEWS!

HKNC-TAC REFUNDED THREE MORE YEARS

HKNC-TAC's goal is to facilitate transition for youth with deaf-blindness through the provision of national technical assistance. To accomplish this goal, HKNC-TAC operates under four objectives, by providing technical assistance to:

- States in developing state and local level interagency teams;
- States in developing local transitional services and model demonstration sites;
- Parents, family members and consumers in supporting the transition process;
- Single and multi-state projects for children with deaf-blindness in conducting individualized transition planning.

Announcing a Call for Technical Assistance Applications!

We are inviting applications in conjunction with our second objective: to provide technical assistance in developing local transitional services and model demonstration sites in the areas of education, employment and community living for transition-aged young adults with deaf-blindness.

Public or private local agencies, organizations or programs, or parent organizations, providing or proposing to provide transitional services to youth with deaf-blindness are eligible to apply for HKNC-TAC services. Eligible applicants include:

- | | |
|-----------------------------|-------------------------------|
| local or state schools | parent/family groups |
| sheltered workshops | supported employment programs |
| leisure/recreation programs | supported apartment programs |
| group homes | day programs |

Eligible applicants are invited to complete a written Technical Assistance Request Application.

Types of technical assistance provided to accepted applicants include:

- On site technical assistance provided by HKNC-TAC staff and/or a consultant;
- A TAC-sponsored training activity or topical workshop;
- A presentation by TAC staff at a non-TAC sponsored training activity or conference.

Examples of technical assistance activities include:

- | | |
|--|--------------------------|
| individualized transition planning (ITP) | communication methods |
| community integrated employment | assistive technology |
| personal futures planning | supported living |
| peer and natural supports | job development |
| behavioral issues | orientation and mobility |

An application for technical assistance must be completed and received by **January 2, 1993**. For an application or more information, please contact:

Ms. Terry Carr, Project Coordinator
HKNC-TAC
111 Middle Neck Road
Sands Point, NY 11050
(516) 944-8900 (V/TDD) FAX (516) 944-8751

Communication and Interaction Map

Guidelines for Use

One special map being developed and tested at HKNC is a "Communication & Interaction Map". This map is useful to help understand a person's individual communication methods. Everyone can communicate, but some individuals may not have a formalized method. The Communication/Interaction Map assists in discovering informal communication methods that might otherwise be overlooked. It can also serve as an invaluable source of information on the variety of communication methods used by both the individual and the key persons in his or her life.

The following guidelines describe how to develop this map. This is followed by sample maps which show the kind of things that might be included.

<p>1. WHO interacts with student and/or activity involved.</p>	<p>List significant people with whom focus person interacts on a regular basis and the activity they are involved in. For example:</p> <ul style="list-style-type: none"> ● Clerk at Burger King Thursdays and Fridays at lunch. ● Job coach at Garden Center ● Swimming volunteer on Wednesday nights ● Mom and Dad ● Julie and Fred at Church (friends)
<p>2. METHODS by student and by others. Put an * next to each method that the student is skilled with.</p>	<p>List all kinds of communicative methods used by the focus person. These can include:</p> <ul style="list-style-type: none"> ● speech/smiling/laughing/vocalizing ● body movements/touching/pointing/gestures/home signs ● manipulating others ● using objects or object symbols or pictures or communication books/boards ● American Sign Language or Sign in English word order ● Tactual sign language ● fingerspelling ● print ● braille OR anything else...
<p>3. WHAT FOR ?</p>	<p>List reasons the focus person communicates with others or others communicate with him or her. For example:</p> <ul style="list-style-type: none"> ● Asking for more ● ask for help ● give a direction ● ask questions ● socializing ● say yes or no ● make a choice ● get information ● answer questions ● and many more.....
<p>4. EXAMPLES OF VOCABULARY</p>	<p>List signs or describe gestures, body movements, objects that the focus person uses. Provide examples of written phrases or vocabulary used in specific situations. If the focus person has an extensive vocabulary, provide some examples.</p>

Communication and Interaction with Joe

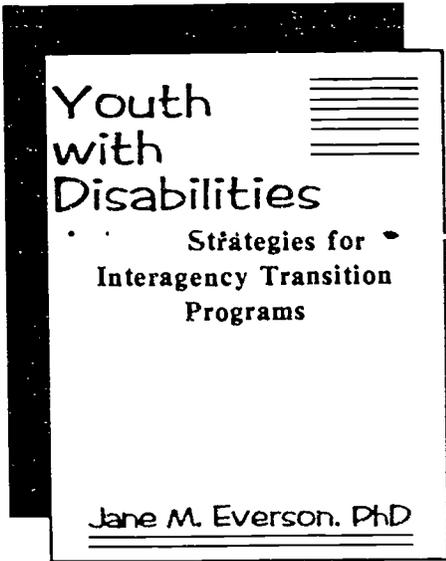
Communication by Student				
Who Interacts With the Student and Activity Involved	Methods	What For?	Examples of "Vocabulary"	Responses by Others
Matty and Day Staff	*Gesture	Change shirt	Pulls at buttons	Provide different shirt & assist in changing it.
Day and Night Staff	*Self injurious & other behaviors	Avoid task	Hits self	Provide choice to do different task.
Matty and Day Staff	Object symbol	Bathroom	Wall tile	Assist in travel to bathroom.
Matty and Day Staff	Actual objects	Choose breakfast food	Picks from 2 food items, e.g., cereal, waffle	Help him prepare the food he has chosen.
Susan and Night Staff	*Manipulates others	Food or drink	Pulls staff to kitchen	Provide choices.

* = skilled/uses often

Communication by Others				
Who Interacts With the Student and Activity Involved	Methods	What For?	Examples of "Vocabulary"	Responses by Student
Matty and Day Staff	Object	Indicate time to shower	Shampoo bottle	Walk toward bathroom.
Day and Night Staff	*Object	Do next part of grooming task	Toothbrush, hairbrush, etc.	Begin task.
Matty and Day Staff	Object symbol, sequence box	Anticipate what will immediately happen next (schedule)	Work card, scissors, lunch box	Holds object, waits for assistance.
Susan and Night Staff	Pointing	Show where bathroom is.	Pointing	Walks to bathroom on his own.
Day and Night Staff	Individual sign language signs	Anticipate what will happen next	**"drink"; **"finish"; "toilet"	Does task.

We periodically meet to update the Communication & Interaction Map and to generate some summary conclusions and suggestions to further facilitate communication. Many times a communication & interaction map highlights the fact that there are few interactions with people other than staff. We look for as many ways as possible to encourage increased and more in depth interactions with people in the community volunteers and peers

Deborah Harlin is the Supervisor of HKNC's Functional Language Programs.



Youth with Disabilities

Jane M. Everson, PhD

This manual provides strategies for planning, implementing, monitoring, and evaluating transition programs for young people with multiple disabilities. The book includes sample forms, checklists, work sheets, case studies, and activities.

Contents:

- Characteristics of Transition Programs
- Using Teams to Bring About Change
- Conducting Program Needs Assessment
- Developing Action Plans
- Implementing Action Plans
- Maintaining the Direction and Focus of Teams
- Evaluating Team Efforts

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"Every human being has undeniable rights which, respected, render happiness possible--the right to live his own life as far as may be, to chose his own creed, to develop his capacities..."

Helen Keller

HELEN KELLER
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VOLUME 6, NUMBER 3

Supporting the Transition of Youth with Deaf-Blindness

FALL, 1993

Personal Futures Planning: Building a Foundation for Individualized Transition Services

Every professional providing transition services to individuals with disabilities no doubt recognizes the importance of individualized services. But during the daily activities of running human service agencies, individualization often becomes an afterthought. Referral procedures, screening and assessment procedures, eligibility requirements, waiting lists, program capacity, funding streams, staff availability, and certification requirements all consume professional time and energy, leaving little time for person-centered thinking and activities. Legislative efforts attempt to remind us of the importance of

person-centered planning with a proliferation of mandated, individualized plans — from IFSPs and IEPs, to IWRPS. But the reality is that most young adults do not receive individualized plans of transition services and supports; instead, they receive whatever services and supports agencies currently have available. Current service availability, not personal wants and needs typically determines the transition opportunities available to young adults with disabilities.

This newsletter provides young adults with deaf-blindness, their family members and service providers with strategies for using personal futures planning and other person-centered activities to build a foundation for individualized transition services. Several key assumptions make up this foundation: (1) person-centered planning is an

invaluable transition assessment and planning process; (2) IEPs can be an effective instrument for designing and implementing transition services; and (3) students with deaf-blindness, their parents and family members, working with professionals are essential players in the process.

What are Transition Services?

IDEA defines transition services as "...a coordinated set of activities for a student...including postsecondary education, vocational training, integrated employment (including supported employment), continuing and adult education, independent living and/or community participation."

A statement of needed transition services must be included within the IEPs of all special education students beginning no later than age 16 "...including a statement of each public agency's and each participating agency's responsibilities and linkages, or both before the student leaves the school setting."

If the IEP team determines that one or more of the specified services are not needed "...the IEP must include a statement to that effect and the basis upon which the determination was made..." [PL 101-476, 20 U.S.C. 1401 (a) (19-20); 1412 (b) (2); and 1414 (a) (5)].

Why are Transition Services so Important for Young Adults with Deaf-Blindness?

Many follow-up studies of former special education students were conducted during the 1980s,

Transition Services & Personal Futures Planning

Technical Assistance Center of the Helen Keller National Center (HKNC-TAC)

HKNC-TAC is a national technical assistance center funded by the U.S. Department of Education, Office of Special Education Programs, Agreement #HO25E90001-93.

HKNC-TAC's purpose is to provide national training and technical assistance to education programs and adult agencies providing school-to-adult-life transition services to youth with deaf-blindness.

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Transition Services & Personal Futures Planning, continued from page one

but only two studies actually isolated and addressed the transition experiences of youth labelled deaf-blind (i.e., Wagner, 1993; Frey, 1988). In Wagner's national and longitudinal study, youth labelled deaf-blind and youth labelled multiply-handicapped were least likely of all categories of former special education students to transition from high school into either part-time or full-time employment, post-secondary technical schools, colleges or universities!

In both studies, youth with deaf-blindness were more likely to live with their parents or in residential facilities than in their own homes and with housemates of their choosing. Frey noted that most former students with deaf-blindness were unable to identify even one friend and seldom participated in recreation and other community activities.

What is Person-Centered Planning?

Person-centered planning is an umbrella term used here to describe the work of Beth Mount, John O'Brien and others in the United States and Marsha Forest and Judith Snow in Canada. Specific approaches are also known as personal futures planning (Mount & Zwernik, 1988), MAPS or the McGill Action Planning System (Vandercook, York, & Forest, 1989). All person-centered approaches can be used to enhance more structured and system-centered service plans, such as IEPs and statements of transition services mandated by IDEA.

All person-centered planning approaches begin with a focus on the wants and needs of an individual and recognize the importance of both formal and informal supports in assisting the person in achieving his or her dreams. O'Brien (1987) summarizes three characteristics of all person-centered planning approaches: (1) everyday activities should be the focus of planning efforts; (2) services are less important than family and community connections; and (3) no single person can or should do everything.

Personal futures planning, because of its focus on future visions and planning activities, is most closely associated with the mandates and goals of transition services. Personal futures planning consists of three components: (1) a personal profile and a future vision map; (2) a planning team or "circle of support;" and (3) an action plan (Mount & Zwernik, 1988).

Personal futures planning is not intended to replace the transition services component of the IEP. Instead, person-centered planning activities can be used to enhance traditional system-centered planning services by guiding teams in using, gathering and managing assessment data, developing interventions, and creating packages of supports that are more person-centered and more visionary.

**A Comparison of Personal Futures Planning
& Traditional Transition Planning Concepts**

Traditional Transition Planning

Personal Futures Planning

A team of service providers meet annually or more frequently as needed with the parents and student to develop a plan for educational and related services.

A circle of support made up of the focus person with a disability, parents, and other family members meet with service providers and general community members monthly or as frequently as needed to develop a future vision for the focus individual and implement an action plan to achieve the future vision.

A transdisciplinary team conducts and interprets assessment data using standardized and non-standardized assessment mechanisms.

A circle of support gathers, organizes, and manages assessment information into a personal profile and future vision using highly visual graphics known as maps.

The student with a disability is invited to participate in the team meeting as appropriate.

The circle defines a role for every focus person and assists the person in assuming the roles in a respected and competent manner.

Parents are invited to participate in the development of the individualized service plan.

Parents, other family members, friends, and general community members define the personal profile and future vision and look to service providers for support.

An IEP with a statement of needed transition services is mandated to guide services.

A future vision and action plan guide the circle's activities and should be used to drive IEP/transition plan content.

Implementation of the plan is ensured through provision of entitlement services, due process, and professional services.

Implementation of the plan depends upon the commitment and energy of the circle of support and their connections with the focus person and family.



• How can Personal Futures Planning Activities be Used to Enhance Traditional Transition Planning Activities?

Step #1: Convene a Circle of Support Around a Focus Person

When a "focus person" with deaf-blindness reaches age 14-16, family members may wish to develop a "circle of support" made up of themselves, other family members, friends, neighbors, other community members who have a relationship with the "focus" person along with the education and adult service providers who are members of the young adult's IEP team. This team will meet separately from the IEP team and will engage in some activities that will enhance, but not replace traditional IEP activities.

Define a role for the "focus person" to play in the circle, for example, to issue invitations for people to attend circle meetings, to participate by communicating dreams and fears, to assist with developing and displaying maps, etc.

Invite all members to one or two circle meetings prior to the first IEP meeting during which transition services will be discussed. At these meetings, develop a personal profile and future vision for the young adult (See HKNC-TAC News, Winter/Spring 1992-1993 for examples of profiles and future vision maps).

Step #2: Use Personal Profile and Future Vision Maps to Update and Compile IEP Assessment and Planning Data

One or more of the circle members will also be IEP team members, for example the parents and teachers. These individuals should bring the maps to all subsequent IEP meetings and describe them to the rest of the team.

One effective strategy for using the maps to direct IEP activities in a more person-centered way is to open the IEP meeting with a discussion of the young adult's future vision. As IEP goals and objectives are developed, team members should ensure that they will assist the young adult in achieving his or her desired vision.

Step #3: Identify Desired Transition Outcomes and Supports to Achieve the Future Vision

Each area of adult life identified in the IEP/transition statement form (e.g., employment, postsecondary education, living arrangements, homemaking activities, transportation, medical and health supports, recreation, friendships, etc.) should be considered and briefly discussed in relation to the young adult's desired future vision. Most of these transition services areas have closely related maps which update assessment data and present it in a more functional way.

Step #4: Develop Related IEP Objectives

Maps allow IEP objectives to naturally follow. The IEP objectives are both family- and person-centered. They are individualized to the personal profiles and future visions of each focus person.

Step #5: Develop and Implement a Team Action Plan to Achieve the Future Vision and Implement the IEP

Two significant differences between an IEP team and a circle of support are: (1) circles of support meet more frequently than IEP teams; and (2) circles make a long-term commitment to acting as a team in assisting the focus person in achieving a future vision. Some team members may decide they are only willing to create personal profile maps and future vision maps and use them to develop more person-centered IEPs. Others may decide to continue circle activities in order to tackle the systemic issues that may arise from implementation of the young adult's future vision. It is important for all team members to assess their connections and commitment to the focus person and define a role with which they are comfortable. Achieving one's future vision is hard, time-consuming work—it may not be a desired role for all service providers, family members or young adults.

Choosing a Person-Centered Transition Planning Form

Across the United States, numerous forms for developing statements of transition services are available — some are infused within IEP forms, others are addenda statements to IEP forms. A form can be an important component of person-centered transition planning activities because it can help guide a team through a discussion of assessment data, desired adult outcomes, and individualized supports needed to achieve the adult outcomes. Service providers and family members may want to evaluate the transition statement form they are currently using with this checklist.

ITP/Transition Planning Form: Choosing and Evaluating a Form

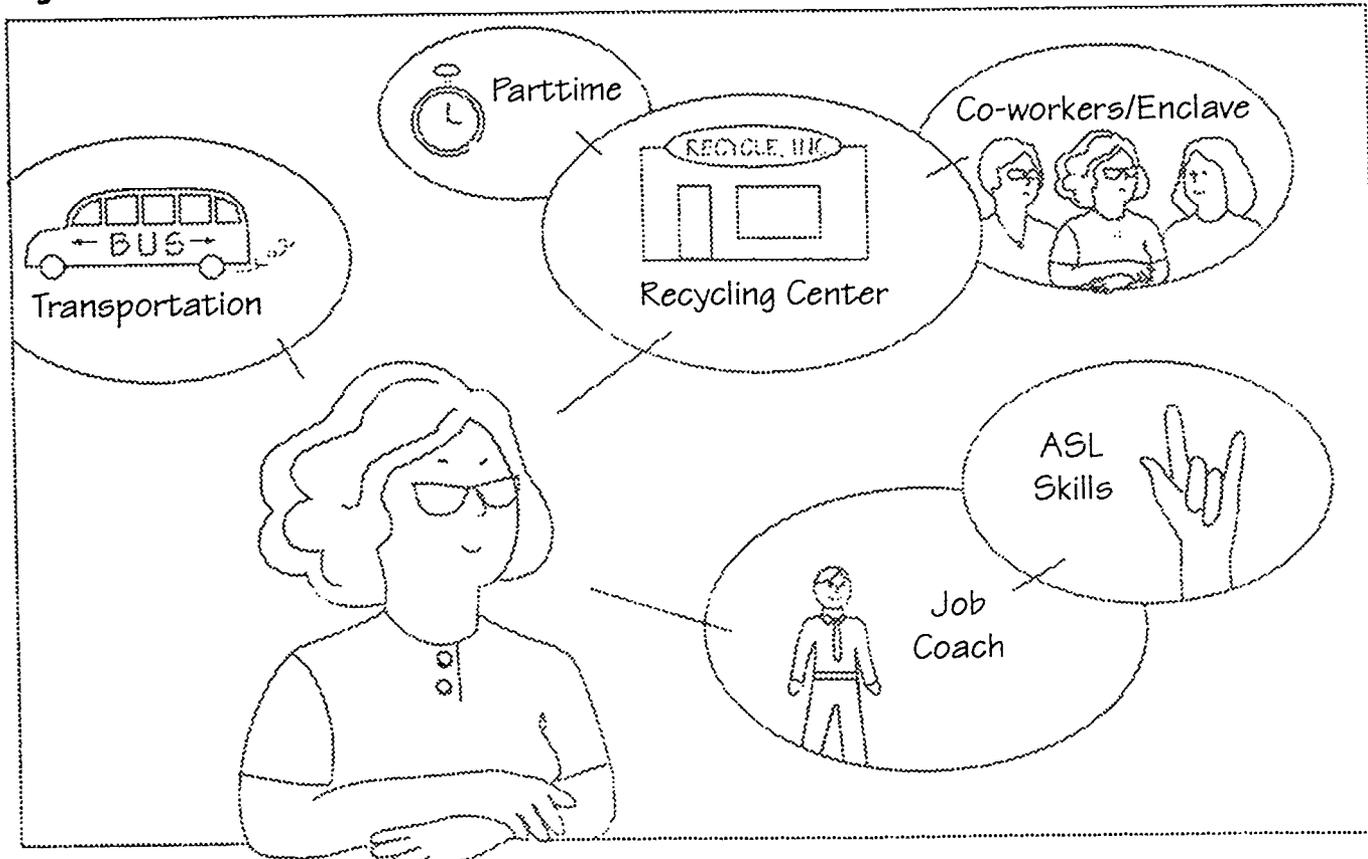
(This checklist can be completed by Teachers, Parents, Support Staff, Students, Administrators, and/or Adult Services Providers.)

	POOR		AVERAGE		GOOD
	1	2	3	4	5
1. The form lists outcome areas identified by IDEA (i.e., post-secondary education, vocational training, integrated employment, continuing adult education, adult services, independent living, and community participation).	1	2	3	4	5
2. The form includes these plus a more exhaustive set of outcome areas (e.g., living arrangements, homemaking needs, transportation, medical, relationships, financial, leisure/recreation and advocacy/legal).	1	2	3	4	5
3. The form includes space for the team to write/expand information on individualized adult outcomes.	1	2	3	4	5
4. The form includes space for the team to define school action steps.	1	2	3	4	5
5. The form includes space for the team to define adult service action steps.	1	2	3	4	5
6. The form includes space for the team to define family action steps.	1	2	3	4	5
7. The form includes space for the team to identify responsible personnel.	1	2	3	4	5
8. The form includes space for the team to identify timelines for completion of action steps.	1	2	3	4	5
9. The form includes space for identifying why one or more outcome areas was not addressed.	1	2	3	4	5
10. The form shows the relationship between IEP goals and transitional services.	1	2	3	4	5
11. The form invites family/student participation and dreaming.	1	2	3	4	5



Using Maps to Identify Desired Transition

Regina's Future Vision Map: Employment



Regina, a 20-year old young adult with deaf-blindness and multiple disabilities

Employment Future Vision: Regina will be employed at a recycling business in a supported employment enclave with two other workers by the time she leaves high school.

IEP Objective: Regina will participate in a 15-week community-based work experience (3 days a week, 2 hours a day) where she will learn to sort glass, aluminum, cardboard, and newspaper using tactual/signed cues. She will sort with 90% accuracy according to task analyses for each task across 15 minute testing sessions.

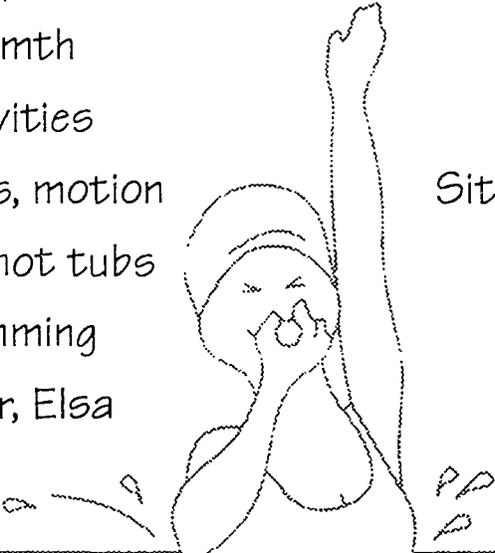
Action Steps: (1) The special education teacher will establish a group community-based non-paid work experience site at the local recycling business (following U.S. Department of Labor regulations) and provide instruction to Regina and her classmates. This will include identifying tactual/signed cues and a prompting system for Regina's new recycling tasks. (2) The rehabilitation counselor will review Regina's work experience data and visit her at least one time at her work experience site to initiate her referral and assessment process to rehabilitation services.



Outcomes, Supports & Related IEP Objectives

Jenny's Preferences Map

<u>Things That Work</u>	<u>Things That Don't Work</u>
Water! Splashing!	More than 4 people in a group
Warmth	Being rushed
Activities	Sitting still for more than 10 minutes
Car trips, motion	Wet, cold clothes
Baths, hot tubs	
Swimming	
Sister, Elsa	



Jenny, an 18-year old young adult with deaf-blindness and multiple disabilities

Recreation Future Vision: Jenny will be a member of the community college health and fitness center and will go swimming there with a family member or friend on a weekly or more frequent basis.

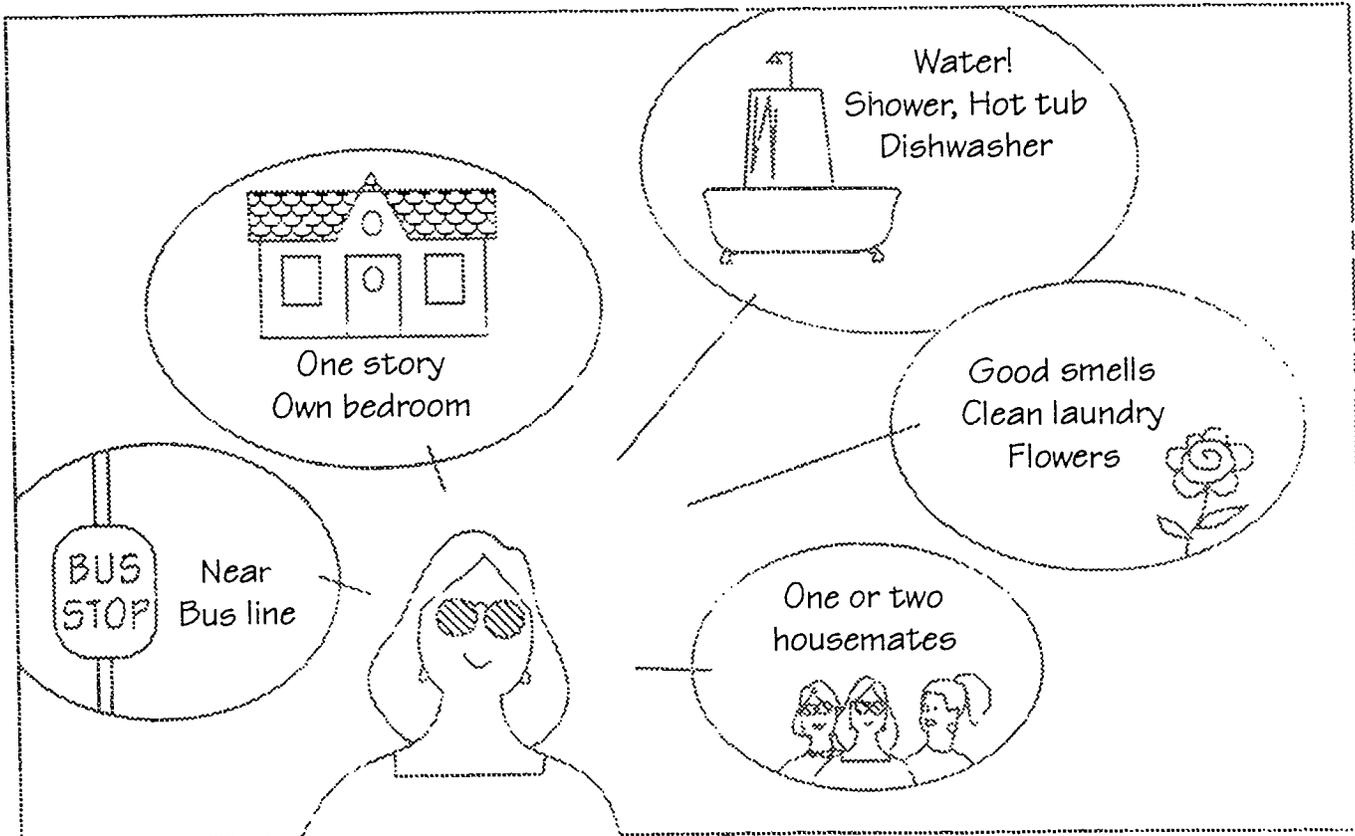
IEP Objective: Jenny will go swimming for 30 minutes once every two weeks with two classmates at the local YWCA.

Action Steps: (1) The special education teacher will provide tactual/signed instruction in dressing and undressing in the locker room, swimming, and using a life jacket. (2) Jenny's family will enroll her in the community college health and fitness club and take her swimming on bi-weekly basis. (3) Jenny's family and case manager or teacher will explore availability of local apartment complexes that have swimming pools.



More Maps to Identify Desired Transition

Nina's Future Vision Map: Home



Nina, a 20-year old young adult with deaf-blindness and multiple disabilities

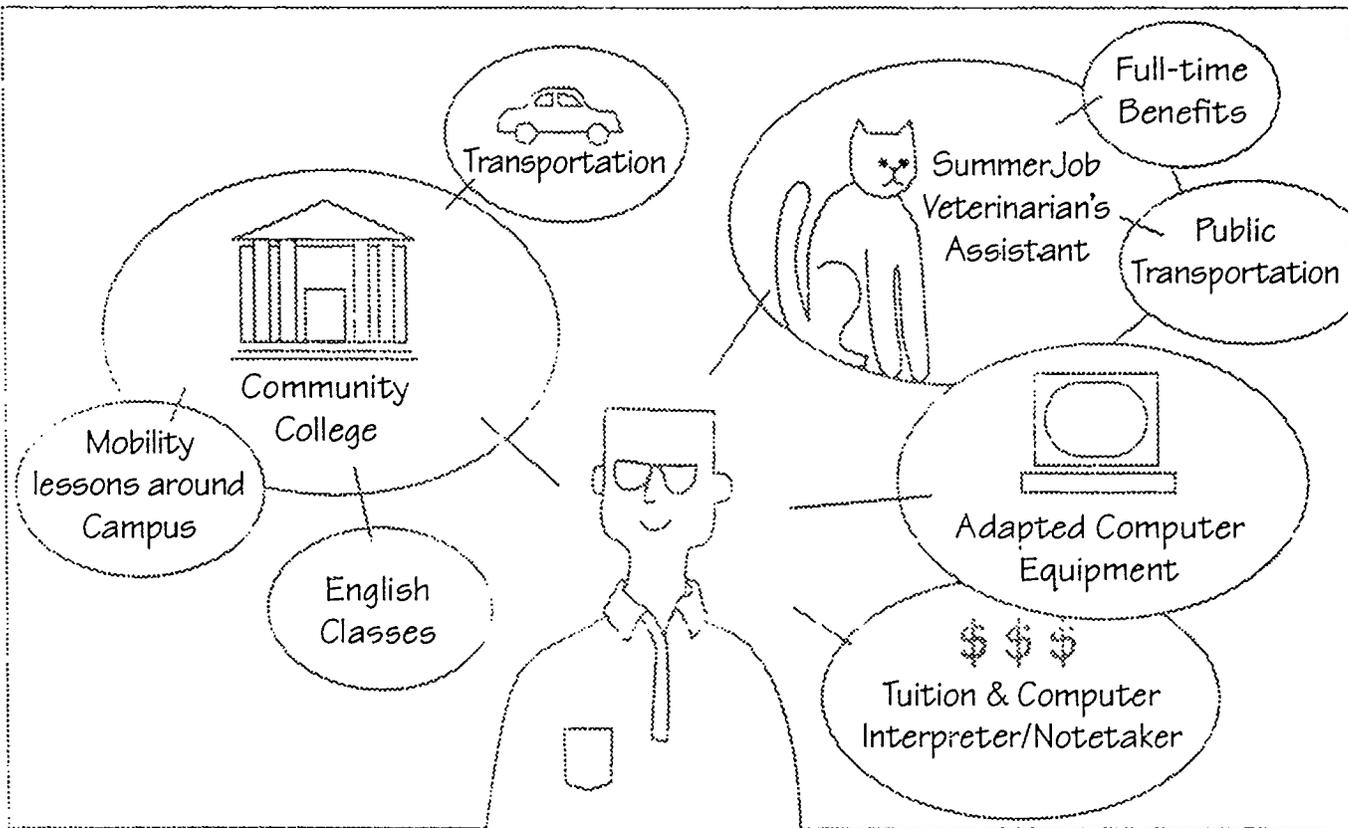
Community Living Vision: Nina will live in a supported home in a neighborhood no more than 30 miles from her parents with no more than two other young adults who can communicate with her.

IEP Objective: (Five days a week, two hours a day.) Nina will learn to prepare a simple breakfast and lunch, fold her laundry, unload a dishwasher, and mop a floor with 90% accuracy according to task analyses at a local group home training site.

Action Steps: (1) Nina's special education teacher will provide tactual/signed instruction using task analyses. (2) Nina's case manager and parents will meet with an identified real estate agent to discuss availability of rental property in the desired neighborhood. (3) Nina's case manager and parents will meet with a representative from the department of social services to explore use of a Medicaid waiver to provide support services. (5) Nina's case manager and her parents will develop a support plan that includes staffing, rent/utilities, furnishings, etc. to present to the department of social services.

Outcomes, Supports & Related IEP Objectives

Joel's Future Vision Map: Higher Education



Joel, a 20-year old young adult with deaf-blindness

Postsecondary Education Vision: Joel will enroll in and complete a two-year animal care technician program at the local community college.

IEP Objectives: (1) Joel will complete a written application, an interview, an orientation visit to the college campus with assistance from his guidance counselor and parents. (2) Joel will increase his English reading and writing ability from a sixth grade level to an eighth grade level with instruction from his classroom teacher. (3) Joel will enroll in a summer paid, work experience at a local veterinarian's office with assistance from his vocational education teacher and rehabilitation counselor.

Action Steps: (1) The rehabilitation counselor will meet with Joel and his parents to develop an IWRP including a plan for summer employment, college tuition, transportation, adapted computer, and interpreter funding. (2) The O&M specialist will provide orientation and route training to Joel at the college campus.



Students with Deaf-Blindness Participate in Transition Planning:

Defining Your Vision

1. What are your greatest dreams?
2. What are your biggest fears?
3. What things might keep you from accomplishing your dreams?
4. How can service providers help you reach your goals?
5. How can family members and friends help you reach your goals?

Thinking About Postsecondary Education

1. What are your favorite classes? Why do you think you're successful in these classes?
2. What are your least favorite classes?
Why do you think you're having difficulty in these classes?
3. How will the classes you are taking now help you reach your dreams?
4. Are you interested in attending college?
How will it help you achieve your dreams?
5. What specific skills do you need that you could learn while you are still in high school?
6. How will you pay for college?
7. What support services do you think you will need in college?
For example, interpreters, visual aids, audiological aids, orientation and mobility instruction?
How do you feel about using these services?

Thinking About Employment

1. What job would you like to be doing 2 years from now? 5 years from now? 10 years from now?
2. What kind of work experiences have you had?
What kinds of things do you think you're good at? What are you not good at?
3. What skills will you need to do the kind of job you want to do?
What kind of training or education do you need for this kind of job?
4. What things are important to you in a job?
For example, salary, benefits, transportation, schedule, location, personality of your boss?
5. What hobbies and interests do you have that might be related to a future job?
6. How can service providers help you get a job?
How can family members and friends help you get a job?

Thinking About Living Arrangements

1. What does your dream house look like?
2. What kind of chores do you do at home that will help you live more independently?
What kind of chores do you need help with?
3. How would you locate housing?
How would you pay for it?
4. What specific skills do you need that you could learn while you are still in high school?
5. How can service providers help you?
How can family members and friends help you?

Questions for High School Classes and Support Groups

Thinking About Financial/Income Needs

1. How do you manage your money now? How will you manage it after you leave high school?
2. How much money do you need to reach your dreams?
3. Are you familiar with SSI and Medicaid? Do you know how to apply for these services?
Do you know who to contact if you have any questions about these services?

Thinking About Community Resources/Transportation/Medical Services

1. What support services are available to you as a young adult with deaf-blindness?
For example, TTY or TDD, assistive listening devices, low vision devices, interpreter services, orientation and mobility services, etc.?
2. What support services are available to anyone who lives in your community? For example, food stamps, counseling services, public transportation, community recreation services, etc.?
3. How would you find out about these and other support services?
4. What kind of transportation do you use now?
What will you use when you finish high school?
5. How can service providers help you? How can family members and friends help you?

Thinking About Leisure/Recreation/Relationships

1. What do you like to do for fun? What are your hobbies and interests?
2. Who are your friends? What characteristics are important to you in a friend?
3. How do your friends help you?
What do you wish they would do more or less of to help you?
4. Are there any activities you wish you could learn how to do?
For example, bowling, swimming, skiing, knitting, painting, etc.?
5. Are there any high school activities you might like to get involved in?
6. How do you involve your friends and family members in your recreation activities?
7. What things prevent you from being involved in the recreation activities you are interested in?
How can service providers help you? How can family members and friends help you?
8. How do you handle crises or solve problems? What kind of things are stressful to you?
9. Whom would you go to if you had a problem or needed help?

Thinking About Medical/Advocacy/Legal Issues

1. Do you have a family doctor and dentist?
How will you take care of your medical and health needs?
2. Do you have an eye and an ear doctor?
Do you know what you need to do to take care of you eyes and ears?
3. Besides vision and hearing, do you have any medical needs that you will need to take care of?
4. If you run into a legal problem, how would you handle it? Who would you go to for help?
5. What do you know about first aid? Who would you contact in case of an emergency?
6. Which service providers can help you with medical or legal needs?
7. What kinds of insurance will you need, and how will you apply for it?



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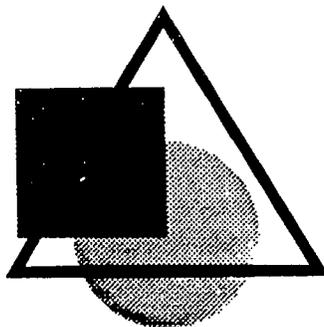
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"Every human being has undeniable rights which, respected, render happiness possible—the right to live his own life as far as may be, to choose his own creed, to develop his capacities . . ." Helen Keller